

Evidence Check

Consumer enablement

An **Evidence Check** rapid review brokered by the Sax Institute for the Agency for Clinical Innovation.
May 2016.

This report was prepared by:

Roy Batterham, Richard H Osborne, Crystal McPhee, Paulina Mech, Belinda Townsend.

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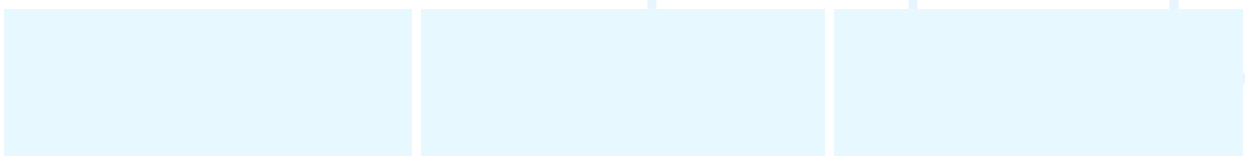
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Contents

Glossary.....	5
Executive summary.....	7
Brief background to consumer enablement and chronic disease	7
Purpose of the review	7
Summary of findings, implications and recommendations	7
Conclusion	8
Introduction	9
Purpose and scope of the evidence check	9
Concepts and definitions	9
Towards models for enhancing consumer enablement for all people	10
Key discourses of enablement, empowerment and self-management	10
Developing a taxonomy of components, determinants and outcomes of consumer enablement	15
Methods	23
Results of Evidence Check.....	29
Question 1: What is the evidence regarding the determinants of consumer enablement in the chronic disease population and what implication does this have?	29
Question 2: What tools and instruments have been shown to be valid and reliable and clinically useful, for which groups, in measuring the drivers and components of consumer enablement?	36
Recommended group assessment tools	39
Promising tools that do not meet all preferred requirements	40
Question 3: What does the evidence show in relation to specific interventions that support self-management for chronic disease and enhance enablement of the consumer?	42
Question 4: What implications arise regarding the identification of the support needs and strategies to support individuals with varying degrees of complexity and enablement?	48
Appendices.....	53
Attachment A: Evidence tables for Question 1	53
Attachment B: Detailed analysis of tools for Question 2	69
Attachment C: Evidence tables for Question 3	90
Attachment D: Grey literature retrieved and searched.....	104
References	130

Glossary

ACI	Agency for Clinical Innovation
AMSTAR tool	A Measurement Tool to Assess Systematic Reviews
ASMC	Efficacy of Arthritis Self-Management Course
BBQ	Beliefs and Behaviour Questionnaire
BMI	Body Mass Index
CALD	Culturally and linguistically diverse
CDESES	Chronic Disease Self-Efficacy Scales
CHAT	Conversational Health literacy Assessment Tool
CINAHL	Cumulative Index of Nursing and Allied Health Literature
CV	Cardiovascular
CVD	Cardiovascular disease
EPPCIC	Expert Patients Program Community Interest Company
ESPS	Empowering Speech Practices Scale
HARP	Hospital Admission Risk Program
HAQ	Health assessment questionnaire disability
Hba1c	Glycated haemoglobin
HDS	Health Distress Scale
heiQ	Health Education Impact Questionnaire
HLQ	The Health Literacy Questionnaire
HSIU	Health Systems Improvement Unit
ICT	Information and communications technology
Medibank PWC	Medibank Price Waterhouse Coopers
MEDLINE	Medical Literature Analysis and Retrieval System Online
MHW	Multicultural health worker
NHS	The National Health Service
NICE	National Institute for Health and Care Excellence.
Ophelia	OPTimising HEalth Literacy and Access to health information and services
PACIC	The Patient Assessment of Chronic Illness Care
PAM	Patient Activation Measure
PEI	Patient Enablement Instrument
PES	Patient Empowerment Scale
PSs	Peer supporters (PSs)
PESS	Patient Enablement and Satisfaction Survey
PHE	Patient Health Engagement
PIH	The Partners in Health scale

PREMs	Patient reported experience measures
PROMs	Patient reported outcome measures
PsycINFO	Database of abstracts of literature in the field of psychology
QoL	Quality of Life
REALM	Rapid Estimate of Adult Literacy in Medicine
SEHCP	South East Healthy Communities Partnership
TOFHLA	Test of Functional Health Literacy in Adults
URICA	University of Rhode Island Change Assessment Questionnaire
WHO	World Health Organisation

Executive summary

Brief background to consumer enablement and chronic disease

Consumer enablement is a complex concept that overlaps with many related concepts, all of which are defined as much by their role in political debate as by careful scientific analysis. For the purpose of this review consumer enablement was defined as *the specific components that combine to make a consumer engaged*. Consumer enablement and related concepts have been shown repeatedly to be associated with a large number of outcomes for people with chronic illnesses. However, the results of studies that have tried to increase enablement as a means to influence outcomes are mixed, often short-term, and limited to people with high underlying levels of enablement.

Identifying and developing strategies to improve enablement and outcomes for people with complex needs and low baseline levels of enablement will require challenging many widely held assumptions and practices. It will also require drawing upon experiences and learnings from other sectors who regularly deal with people with complex interacting needs, for example, social services, drug and alcohol services, aged care services, and HIV/AIDS services.

Purpose of the review

This evidence check is part of a model development process in which the Agency for Clinical Innovation (ACI) in NSW is looking to develop a framework that outlines the range of strategies that can be employed to optimally enable consumer participation in the management of their healthcare and ongoing treatment decisions. The Framework will describe interventions that would be most suitable for specific cohorts, depending on the consumers' levels of activation and degree of medical complexity, allowing health services to tailor the method, approach or strategy needed, to individual consumer needs. The end goal is to help consumers to become active managers of their own health and health care, to remain in good health and to avoid hospitalisations. The guiding questions are:

- What is the evidence regarding the determinants of consumer enablement in the chronic disease population and what implication does this have?
- What tools and instruments have been shown to be valid and reliable and clinically useful, for which groups, in measuring the drivers and components of consumer enablement?
- What does the evidence show in relation to specific interventions that support self-management for chronic disease and enhance enablement of the consumer?
- What implications arise regarding the identification of the support needs and strategies to support individuals with varying degrees of complexity and enablement?

Summary of findings, implications and recommendations

The development of a framework to enhance enablement, with a focus on people with complex conditions and low baseline levels of enablement, is a challenging endeavour. The core requirement is the ability to be responsive to people in diverse situations with diverse levels of enablement. Such responsiveness has two core requirements:

1. The ability to assess and describe complexity and the enablement level/profile of: a) individuals, and b) specific target groups, for example, users of a particular service, older people with type 2 diabetes
2. The ability to effectively respond to people's identified enablement status.

To assess and describe peoples' enablement status we consider four categories of components of enablement:

1. Cognitive components including knowledge
2. Affective/motivational components
3. Physical components
4. Relational components.

When we talk about different levels of enablement, we are referring to the different strengths and weaknesses people may have across each of these components.

On this basis, we consider the requirements for a system that is responsive to complexity and different levels of enablement in a two-by-two matrix.

Matrix of areas of response to levels of complexity and enablement

	Assessment and description of complexity and enablement	Planning and implementing responses
Individual	<p>No tools are sufficiently valid to be used to guide decision making about individuals without supplementing the use of the tool with client-practitioner discussion and additional assessments.</p> <p>The Partners in Health scale (PIH) was developed as an aid to joint decision making. Other tools have some potential to be used in a similar way (e.g. heiQ, HLQ, CHAT).</p> <p>A number of tools provide useful assessment checklists for enablement (e.g. BBQ, HLQ, heiQ, HDS, ESPS, PHE).</p>	<p>In general, as you move from higher to lower levels of enablement there is a need for strategies that include:</p> <ul style="list-style-type: none"> • More attention to specific life circumstances including relationships, daily activities (time structuring) and physical and social environments • More emphasis on breaking information provision, goal setting and action planning down into small, practical chunks that are reviewed regularly • More attention to identifying and addressing specific barriers • More consideration of how people gain or lose confidence in themselves and health services through their success and failures in seeking to care for their health.
Group	<p>No one tool was identified that captures the multidimensional nature of enablement.</p> <p>The Health Literacy Questionnaire (HLQ) contains several robust scales suitable for needs assessment, quality monitoring, and outcomes assessment.</p> <p>The Patient Assessment of Chronic Illness Care (PACIC) and PIH may also have a role in quality monitoring.</p>	<p>Strategies to increase responsiveness include:</p> <ul style="list-style-type: none"> • Interventions with health service personnel or community agencies that enable these personnel to practice in ways that are more responsive to peoples’ different strengths and weaknesses (need to give personnel skills, authorization and time) • Interventions aimed directly at consumers • Participatory, data driven processes involving health care agencies and consumers are necessary to develop common understandings.

Conclusion

Development of a responsive intervention framework for enablement will require moving beyond traditional assumptions, specifically recognising that:

- Enablement has multiple components and people can have different strengths and weaknesses. One-size-fits-all approaches are unlikely to be effective
- Enablement is not only about compliance with the expectations of health personnel; it is also about choice and people’s ability to integrate care of their health with the demands of life
- Some aspects of enablement are hierarchical: some needs must be met before others
- Levels of enablement fluctuate due to either short-term crisis issues or long-term negative or positive cycles in which people gain or lose skills and confidence based on their experiences
- Enablement is not only about the individual, it is also about the characteristics of health services people must deal with and the social groups in which they spend their lives. Enablement is influenced by the ways in which health services actively support it and by the nature of a person’s family and support networks.
- Much evidence about ways to work with people with low enablement comes from the grey literature and from other areas in the health sector.

Introduction

Purpose and scope of the evidence check

This document reports on an evidence check conducted by the Health Systems Improvement Unit (HSIU) at Deakin University, commissioned by the Sax Institute on behalf of the Agency for Clinical Innovation (ACI) in New South Wales (NSW). ACI is the lead agency in NSW for promoting innovation, engaging clinicians, and designing and implementing new models of care. This evidence check is part of a model development process in which ACI is looking to develop a framework that outlines the range of strategies that can be employed to optimally enable consumer participation in the management of their healthcare and ongoing treatment decisions. The framework will describe which interventions would be most suitable for specific cohorts, depending on the consumer's levels of activation and degree of medical complexity, allowing health services to tailor the method, approach or strategy needed, to individual consumer needs. The end goal is to help consumers to become active managers of their own health and health care, to remain in good health and to avoid hospitalisations.

The Evidence Check has been conducted to provide background knowledge and understanding upon which to base this framework and specifically seeks answers to the following broad set of questions in the context of the population with, or at risk of, chronic conditions:

1. What are the elements that determine consumer enablement?
2. What tools are available to measure these elements and overall consumer enablement?
3. What interventions and monitoring mechanisms aimed at supporting self-management are effective and can be used within the NSW Health system?
4. What are the guiding considerations and factors to take into account in order to tailor strategies to best meet the needs of a heterogeneous population of individuals with varying degrees of medical complexity and levels of enablement?

Concepts and definitions

For the purpose of this review, consumer enablement is defined as *the specific components that combine to make a consumer engaged*.

This definition raises many questions, most notably, what are the things that we need to consider as the specific components of enablement? Options include:

- Individuals and their cognitive, psychological and physical characteristics
- Characteristics of the health system that either facilitate or hinder access, appropriate use and uptake of advice
- Characteristics of the person's physical and social environment that either facilitate or hinder engagement
- Activities carried out by health providers or others to enhance the above conditions.

The concept of consumer enablement is difficult to pin down precisely due to a number of issues:

1. The concept has considerable overlap with a number of related concepts such as patient empowerment, patient activation, participatory decision-making, consumer engagement, patient enablement, self-management capacity, health literacy and many variants. Attempts to differentiate and define these concepts have not reached agreement.¹
2. Even if some consensus on definitions and differentiation was achieved within the academic literature, the way in which the term 'consumer enablement', and all related terms, are used in practice for policy, debate and decision-making, is often very different to the technical definitions. Often the meanings are more related to the perspectives and priorities of the different stakeholder groups than to any

precise definition. The terms need to be understood as part of a political discourse related to the priorities and needs of these different groups because it is very often these informal understandings that determine how the concepts are applied in practice (see point 3 for example).

3. A key aspect of the previous point relates to the question 'Enablement for what?' Different stakeholder groups tend to see this in different ways, for example:
 - a. Policy makers and bureaucrats often focus on autonomy and the reduced need to use public resources
 - b. Clinicians and public health practitioners often focus on a set of ideal, normative personal health care behaviours
 - c. Consumers often focus on choice and the person's ability to live their life and participate in activities and social roles in the manner that they wish; they seek to minimise the impact of illness on their lives.

There is a need for understanding between different stakeholder groups. Where possible it is important to identify common ground and areas of agreement regarding health outcomes and impacts on social capacities.

4. The ways in which the term is discussed often reveal unstated assumptions that are questionable and may lead to negative consequences for some groups of consumers. Examples of such unstated assumptions:
 - a. 'Enablement' is often thought of as a relatively stable characteristic of individuals rather than as something that may fluctuate due to the circumstances that people find themselves and their accumulated experiences (that is, a trait rather than a state)
 - b. Enablement is often thought to be a characteristic of individuals rather than of family, groups, peer groups, or communities
 - c. Enablement is often talked about as if it was a single characteristic rather than a complex set of characteristics, in which people may have varying strengths and weaknesses and utilise different styles in how they approach self-care (for example, autonomous versus interactive styles)
 - d. Enablement needs are the same across all levels of enablement, and the goals and general strategies (knowledge and skill development, enhancement of motivation, developing autonomy) should be the same for all people.

When these assumptions are stated as baldly as above, many people would contest them. Nonetheless, these assumptions are often evident in the ways in which people discuss and plan about consumer enablement and related concepts.

Towards models for enhancing consumer enablement for all people

The main purpose of this Evidence Check is to support the development of a framework that:

"...will describe which interventions would be most suitable for specific cohorts, depending on the consumer's levels of activation and degree of medical complexity, allowing health services to tailor the method, approach or strategy needed, to individual consumer needs."

In other words, the task is to develop a framework that explicitly recognises and responds to diversity. This task requires us not to be locked in to certain political discourses or bound by assumptions that are not supported by evidence.

Some of the assumptions listed above are briefly discussed in the following sections.

Key discourses of enablement, empowerment and self-management

In the literature about self-management and consumer empowerment many authors, such as Greenhalgh ², Kendall and Rodgers ³, and Thorne and Patterson ⁴, have contrasted the modern normative discourse that focuses on people achieving a set of ideal behaviours with more long-standing discourses of self-

management and empowerment. These conceive self-management as a lifelong process that Kralik et al. describe as a “quest for ordinariness”.^{5,6} This involves managing the changes in the sense of self that accompany life with a chronic illness and solving problems in order to participate in as normal a range of activities (as judged by the person) in as normal a manner as possible:

“...if you want to do something then work out how to do it and what you need to do it...you can usually find a way to get things done.”⁶

In the earlier discourse, ‘empowerment’ was defined in terms of the ability to make choices and live as close to normal a life as possible (as judged by the person); whereas in recent discourses ‘empowerment’ is conceptualised as having the skills to comply with a set of behaviours that are, epidemiologically, beneficial to health outcomes. Greenhalgh refers to the recently dominant approach as the ‘self-management approach’ and the earlier approach as ‘coping with illness’.² She notes that many of the grand hopes for the self-management approach have not been met and presents evidence that many of its fundamental assumptions lack an evidence base. Greenhalgh identifies four main discourses in which concepts such as empowerment, enablement and self-management can be defined and applied (Table 1).

The most prevalent discourse currently is self-management, described in the first row. It can be described as normative (that is, based on a set of ideals) reflecting the expectations and ideals of policy makers and health care personnel. Such approaches have been criticised as intrinsically inequitable and it has been suggested that they in fact increase health inequalities.² This occurs because they tend to split the population into two groups, those who can come close to meeting the ideal, and those who cannot.

Table 1: Perspectives on public and patient involvement in managing chronic illness ²

Different perspectives on patient and public involvement in preventing and managing chronic illness						
Approach	Framing of patient's involvement	Framing of lay involvement	Framing of health professionals' role	Assumed model of change	Preferred research design	Definition of success
Self management (conventional medicine and nursing, drawing on cognitive psychology)	Following a self management plan, which requires psychological resources (eg, self efficacy) and skills (eg, injecting)	Lay trainer (expert patient)	Trainer, adviser	Cognitive development (gain in knowledge, skills, and motivation)	Randomised trial, psychometric questionnaire	Compliance with management plan; change in disease or risk markers and psychometric attributes
Coping with illness (sociology of health and illness, drawing on narrative theory)	Constructing a coherent self; getting on with life despite chronic illness	Peer supporter (witness, role model, conveyor of experience of coping)	Witness, supporter	Emplotment (life unfolds unpredictably; response must be pragmatic, adaptive, coherent)	Naturalistic (eg, ethnography, narrative interview)	Patient copes with life. Professional comes to understand, value, and seek to enhance the lived experience of illness
Whole systems approaches (drawing on social ecology)	Developing and achieving a holistic, personalised care plan, drawing on available resources in the community	Engaged citizen, aligned with prevailing norms and values, seeking to develop health and community services	Coach or guide; partner in social learning and participatory change	Organic (multilevel, whole system change)	Participatory action research, usually linked to mainstream services	Emergence of new structures and opportunities for supporting healthy living and managing illness
Critical public health (drawing on critical sociology)	Recognising and challenging structural barriers to good health (eg, poverty, discrimination, social exclusion)	Engaged citizen, opposed to prevailing norms and values, seeking social justice (eg, resistance, revolution)	Potential oppressor (perhaps agent of the state), or radically	Dialectic (social change)	Political action research, outside mainstream services, and driven by clear values framework eg, equity, democracy	Fundamental change in the social and political structures that constrain individual action and underpin health inequalities

The assumption that enablement is a relatively stable characteristic of individuals

While the discourse around enablement often focuses on the characteristics of individuals, this is at odds with dictionary definitions of the term enablement as **the act of enabling**.⁷

In considering the role of the individual in enablement, rather than focusing solely on the individual's cognitive, psychological and physical characteristics, it may be better to think of the individual as the point at which a range of external and internal 'components' are integrated in such a way that the person feels more enabled, and is practically more able to act in ways that are beneficial to their health. In this regard, the use of the word 'combine' in the working definition of enablement given at the start of this section is particularly important. Fumagalli et al.¹ call this aspect of patient empowerment 'an emergent state' and they contrast it with empowerment as activities that aim to enhance peoples' power (the act of empowering), and with views of enablement as evidenced by certain participatory behaviours. As shown in Figure 1 they consider that enablement, empowerment, activation and engagement are best considered as either emergent states or the activities conducted to bring about these states.

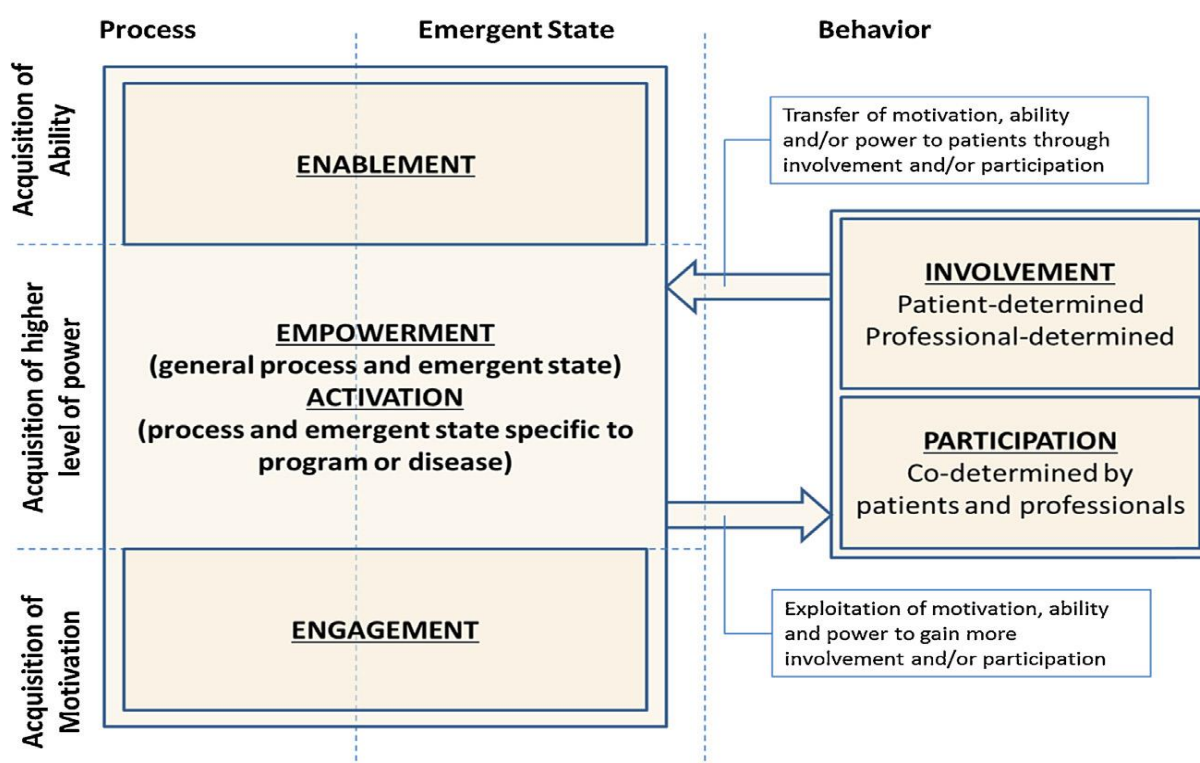


Figure 1: Tentative concept mapping of concepts related to enablement¹

The importance of external factors in enablement is highlighted if we consider the valuable role that a long-term trusting relationship with a GP has on people's perceived ability to care for their health and the likelihood that they will actually do so.

In referring to enablement as an emergent state Fumagalli et al.¹ are recognising that it is subject to both short and long-term fluctuations. Everyone has had experiences where we have felt disempowered, stuck or even paralysed and unable to take care of the various aspects of our life as we know we should. This can happen in times of acute stress, grief, loss or risk. Even senior medical personnel with considerable knowledge, social and financial resources behind them can find themselves in circumstances where they feel completely unable to do the things necessary to care for their health. It is also common for people to experience longer-term fluctuations in the extent to which they feel enabled. This may occur because people experience an acute episode such as those just described and fail to recover. It may occur as a result of negative cycles that progress over time as people's confidence in their own abilities and/or trust and willingness to engage with health services erodes due to a series of negative experiences.

Table 2: Examples of negative and virtuous cycles

Negative (dis-enabling) cycles	Virtuous (enabling) cycles
<p>Example 1: falls risk</p> <ul style="list-style-type: none"> A negative cycle related to risk of falls in the elderly can be triggered by a fall or an episode of illness which then leads to fear of falling, which leads to less willingness to undertake physical activity, which leads to deconditioning and loss of confidence, which leads to more risk of falls and fear of falling and so on. 	<p>Example 1: a new activity</p> <ul style="list-style-type: none"> A person in their 50s has a child who reaches their teen years and becomes very interested in soccer and tennis. These activities become a main focus of family time and the person loses a lot of weight and gains fitness.
<p>Example 2: becoming disheartened</p> <ul style="list-style-type: none"> A middle aged worker faces a period of high stress and conflict at work. He finds sleeping difficult, and stress and tiredness make it harder to fit regular exercise into his day. His eating times become irregular. At the end of six months he has put on 6 kilograms and when he tries to exercise it feels difficult and he is disappointed in himself for losing so much ground. This makes it even harder to be motivated to exercise. 	<p>Example 2: someone who listens</p> <ul style="list-style-type: none"> A person with long-term back pain has started to feel depressed about their situation and often feels judged by people they talk to about it. One day they ended up speaking with a new GP who asks detailed questions about how the pain impacts this person's daily life. They identify two key activities that the person wanted to be able to do and developed strategies to enable them including planning the use of medications. The person ended up being able to apply these strategies in other areas of life.

When we consider people with low levels of enablement, it is therefore critically important not to label them as deficient or flawed (that is, a poorly enabled person), but to consider instead the journey that may have led them to feel dis-enabled and made it difficult for them to act for the benefit of their health. It is necessary to think about a path back to enablement, the barriers that need to be overcome on that path, and the factors and experiences that will develop confidence and capability.

It is also important to note that it is often more useful to think of enablement as a characteristic of family groups, social networks and sometimes even of health services and systems, than as a characteristic of individuals. As noted above, positive and negative interactions with health services and others can either build or undermine confidence, skills and trust. In addition, many health actions are decided and acted on at a family or community level (or are easier to act on at a group level).

Three orientations to consumer enablement

The way we think about concepts like consumer enablement tends to be guided by metaphors that while largely unconscious, influence the extent to which we can respond to people with different enablement needs. Broadly speaking, there are three possible orientations to how we think about consumer enablement.

- 1. Uni-dimensional, normative orientation:** this orientation assumes that enablement is manifested in more or less the same way in everyone, and that it is therefore possible to define a list of ideal criteria of good enablement and to assess the extent to which people meet these criteria. This orientation simplifies measurement and planning by making it more or less the same for everyone. It fails to recognise, however, that people can have different strengths and weaknesses and that there may be different pathways people follow in taking care of their health that are suitable for their particular strengths.
- 2. Multi-dimensional, descriptive orientation:** this orientation recognises that consumer enablement has multiple and distinct components and that people have distinct strengths and weaknesses and distinct styles of engagement (for instance, a style that draws heavily on a relationship with a GP versus a style where a person prefers to be very independent). This orientation emphasises the possibility of using different approaches to strengthen the abilities of different people.

3. **A hierarchical orientation:** this orientation hypothesises that consumer enablement is layered and that there are certain needs that must be met to some extent as a foundation on which responses to other needs can be built (similar to Maslow's hierarchy of need). For example, it may be that trusting at least one health care provider is a pre-requisite for seeking and finding medical advice. People with different levels of enablement may have different needs and require different strategies to be able to progress up the hierarchy (see Table 3).

While each of these orientations has something to offer and none captures the complete picture, the latter two approaches offer more alternatives and guidance for strategies for assisting people who are currently disengaged and people who are hard to reach.

Summary: Conceptual requirements for a responsive framework

Consumer enablement can often be characterised by a range of unspoken assumptions and these assumptions can lead to a homogenised view of enablement that produces disadvantages for groups of people who don't fit these normative expectations. We propose that any approach attempting to be responsive across all levels of enablement must recognise that:

- Enablement has multiple components and people can have different strengths and weaknesses. People may have different preferred styles of caring for their health (for example, an interactive versus an autonomous style) according to their strengths. One size fits all approaches to enablement are likely to be ineffective with substantial sections of the community.
- Enablement is not only about compliance with the expectations of policy makers and health providers, it is also about choice and people's ability to integrate care of their health with the other demands, aspirations and problems of life. It can also be about the ability to advocate on behalf of yourself or people you care for.
- Some aspects of enablement are layered and hierarchical: some needs must be met, at least in part, before others.
- Levels of enablement fluctuate due to circumstances, experiences and the existence of other problems. These fluctuations can be due to short-term crisis issues or long-term negative or positive cycles affecting trust, confidence and engagement.
- Enablement needs differ across the life-course and across the illness journey.
- Enablement is not only about the individual:
 - It is also about the characteristics of health services: people will feel more enabled if they are interacting with user friendly health services and with people who help them develop trust and confidence, rather than undermining these.
 - Enablement is often about families, peer groups and communities, particularly in highly communal cultures where group decision-making may be more common than individual decision-making.
- It is necessary to look beyond the literature that focuses only on chronic diseases. In recent years the literature about chronic disease management has tended to focus on certain standard ideals and approaches. There is considerable experience and published literature from other fields about strategies for effectively engaging people with low levels of enablement and complex needs (for example, drug and alcohol, HIV and disability sectors). The most important insights and approaches may not come from the chronic disease management literature.

In view of these principles a number of steps were included in the strategies for searching the academic literature and the grey literature to identify issues and needs, measurement tools and interventions relevant to people with low levels of enablement, complex needs or specific cultural characteristics.

Developing a taxonomy of components, determinants and outcomes of consumer enablement

There are many challenges in defining the boundaries and relationships between components, determinants and outcomes of consumer enablement. These challenges are exacerbated when we attempt to review empirical evidence and are often forced to use studies in which changes in behavioural outcomes are taken to indicate changes in enablement, despite many problems in making such assumptions. This is not a new problem; the same issues have confounded attempts at definition and conceptual clarification for many concepts with substantial overlap with 'consumer enablement'; that is, concepts such as 'self-

management capacity', 'health literacy', 'patient empowerment' and 'patient activation'. Overall, 'consumer enablement' can be considered a broad and inclusive term that includes many aspects of the other concepts, although it shares with them problems of demarcation between the concept itself and its determinants and outcomes.

In addition, all the concepts identified above tend to be defined in terms of an ideal so that when measurement of enablement occurs it is based on the characteristics of the fully enabled person and how far others fall short on these characteristics. The problem with this approach is that there may be components of enablement that are not relevant to people at high levels of enablement that may be profoundly important at low levels. This logic suggests that it is important to not only consider ideas about enabling factors at one end of the spectrum, but also to carefully consider dis-enabling factors at the other end.

A second problem of definition and conceptualization with 'consumer enablement' and all related terms is that they are all relative to the context in which people find themselves as they seek to manage their health. People need higher levels of personal knowledge, skills, energy and confidence:

- In health systems that are fragmented, bureaucratic, technical, and unfriendly than they do in health systems that are highly user friendly
- When they are facing multiple complex health problems than when their health issues are straightforward
- When their life is complicated by many conflicting priorities, demands and issues than when their life is in a period of stability
- In situations where social networks and pressures present barriers (rather than in situations where they are highly supportive).
- In situations where a person's cultural and religious beliefs are different to the norms of the people around them
- In situations where the cultural and religious beliefs of a person or community group is different to the assumed norms in the health system.

The importance of context

While there may be components of 'consumer enablement' common to most people, whether they end up feeling and acting as enabled people has as much to do with these contextual issues as with the characteristics of the people themselves. In thinking about determinants of 'consumer enablement', the contextual issues listed above have some influence on the components of enablement themselves, but they have an even greater impact on the adequacy of a person's level of enablement, that is, on the relationship between enablement and outcomes.

- Based on these considerations we propose a model of relationships between determinants, components and outcomes of evaluation, as shown in Figure 2. Following this we will further discuss each aspect of the diagram. At this stage it is worth noting that there are three categories of determinants: external determinants, personal determinants, and dynamic determinants based on peoples' positive or negative experiences in attempting to care for their health.
- The external and dynamic determinants are particularly important to identify as they are frequently modifiable and offer a means whereby policies and practices in health service delivery and health promotion can influence enablement of individuals and communities. On the other hand, many of the personal determinants are difficult to change in the short-term (for example, education levels, language skills, core health beliefs). A better strategy may be to consider how to accommodate and work with these factors in building enablement.

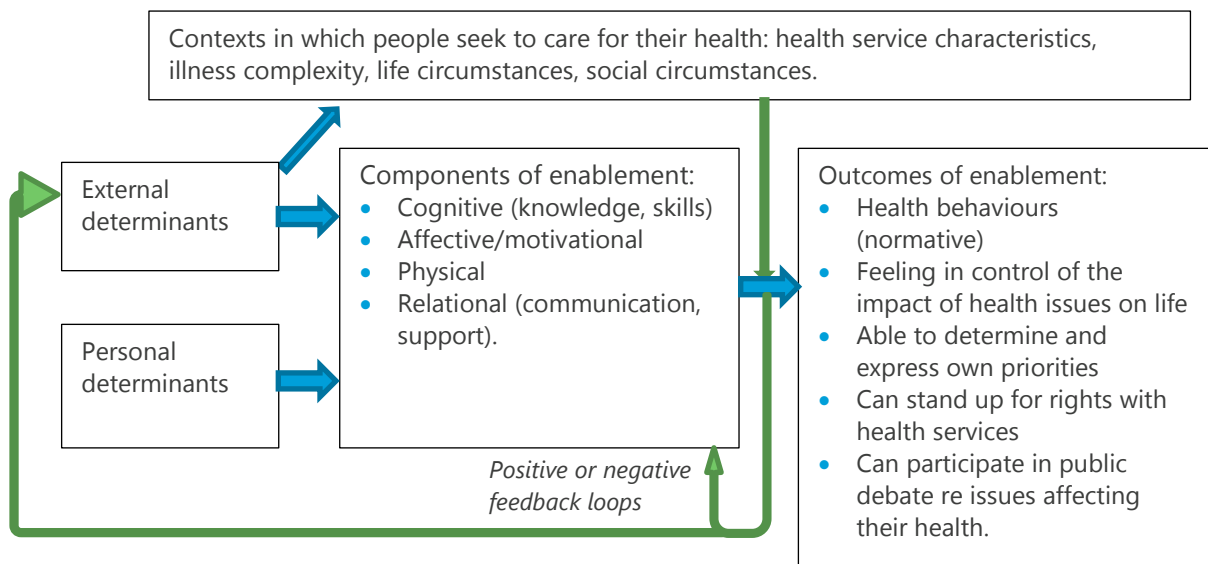


Figure 2: General model of determinants, components and outcomes of consumer enablement

Components of enablement

We define the components of enablement as aspects of a person or group of people that have a direct effect on their ability to care for their health and/or to manage the impact of health issues in their lives. The boundaries between determinants and components is not always clear, but we consider that the components of enablement always have a direct functional influence on how well a person or group is able to manage their health. The following examples of personal factors illustrate the dynamic relation between determinants and components of enablement:

- A person's general confidence that they can get what they want out of life is a personal determinant of enablement; their confidence that they can identify and access needed health services and/or make specific changes in their lifestyle are components of enablement
- A person's level of stress is a determinant: the feeling that they are too overwhelmed to act on their health issues is a component of enablement
- Low fitness and/or fatigue are determinants: the inability to be physically active, to look after their health or do basic activities involved in health care are components of enablement
- A person's general education level is a determinant: their knowledge of and/or ability to find information related to specific health needs is a component of enablement.

Clearly, there may be overlaps between components and determinants of enablement depending on the context. Another way of thinking about the components of enablement is that they tend to be potentially modifiable in the short to medium term, either directly or through the use of compensatory strategies. The determinants of enablement are often, but not always, longer term characteristics of people or their circumstances that are difficult to directly modify.

We consider that most components of enablement can be grouped under four broad headings:

1. Cognitive components including knowledge
2. Affective/motivational components
3. Physical components
4. Relational components.

As discussed earlier the importance of specific components of enablement may be different in people with overall high levels of enablement compared with people with overall low levels of enablement. For example, the relative importance of relational versus cognitive components may be greater for people with low overall levels of enablement (see Table 12 in the section on Question 4). The relative importance of the four categories of components will also vary with people's circumstances. It is also important to note that there is a possibility of positive and negative cycles in relation to each category of components. Sample descriptions of low through high levels of enablement for each category are provided in Table 3.

Finally, it is important to note that strengths in one category may compensate for weaknesses in another. For example, a person who has little knowledge about health issues and few skills in knowledge acquisition and problem solving may nonetheless look after their health very well just by following the advice of a trusted doctor with the assistance of a supportive family.

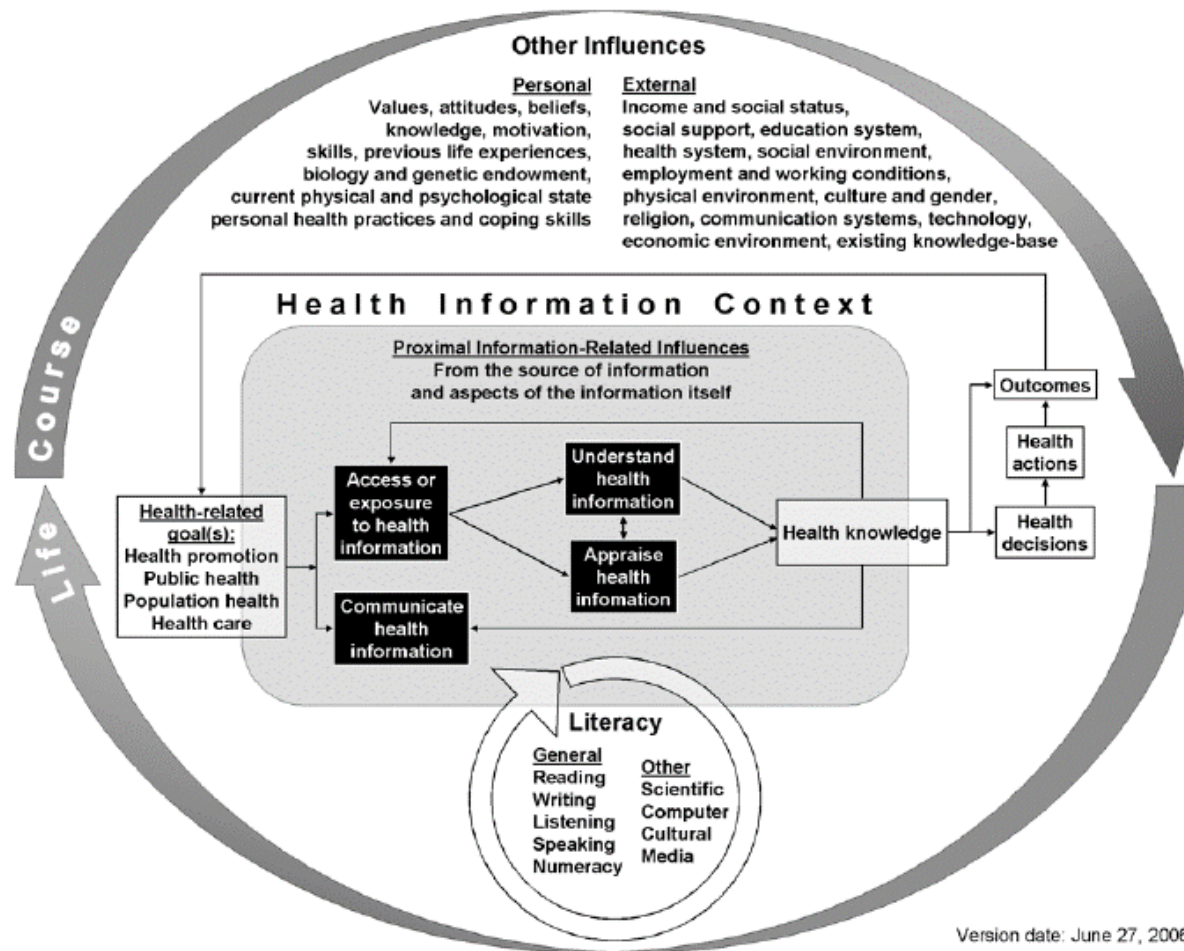
To help illustrate the concept of components of enablement and their varying importance and impact across different overall levels of enablement, Table 3 provides descriptions of characteristics of clients from an extensive set of case studies conducted with a Hospital Admission Risk Program (HARP) in Victoria.⁸ The table describes typical characteristics of people at high, medium and low levels of enablement for the four categories of components.

Determinants of consumer enablement

For many concepts similar to consumer enablement, planners and researchers have identified two broad categories of determinants: personal factors and external factors. The model by Kwan et al.⁹ in Figure 3 is typical of such models.

Table 3: Characteristics of enablement components at different levels

	Low	Medium	High (HARP pop)	High (general community)
1. Cognitive components including knowledge	Lacks insight in relation to their current limitations or health risks. Unable to participate in decision making. May lack knowledge of basic concepts related to health or disease and hold several false beliefs.	Limited ability to understand cause and effect relationships between health related behaviours (including compliance with treatment) and health outcomes. Limited ability to formulate action plans related to goals.	Understands the relationship between personal health behaviours, compliance with treatment and expected health and personal benefits. Able to form coherent action plans in relation to goals (with or without assistance)	Has a good understanding of concepts of biology and causes of health and illness. Confident in ability to find and access services as required. High ability to find understand and use information independently
2. Affective/ motivational components	Psychological state makes it difficult to consider medium or long-term issues. May have difficulty dealing with day-to-day motivation. OR Rejects the need to change or has other priorities which consistently override health care priorities	Expresses willingness to change and a desire to improve health status. May have difficulty following through on actions but generally cooperates with treatment or actions initiated by others.	Able to follow-through on agreed actions and initiates some actions to better participate in health care or to improve health. May still face difficulties with periods of relapse and/or require assistance to overcome set-backs such as acute health events.	Has established routines for maintaining health and fitness that they can maintain with minimal support from friends and family. Invests time and energy into finding out how to improve health and into planning steps to do so and implementing these steps.
3. Physical components	Severely limited in their ability to undertake self-care and basic health care tasks or participate in any health promoting activities.	Physically capable of doing most self-care and health care tasks independently though may need some assistance with transport. Limited ability to achieve physical activity levels necessary to maintain or improve their health.	Physical limitations not a barrier to participating in self-care and health care tasks and achieving a level of physical activity sufficient to produce improvements in fitness and physical status.	No physical limitations affecting ability to maintain a high level of health and fitness
4. Relational components	Has lost trust in health providers and/or feels they have lost trust in him/her. Has no relationships with a trusted provider. May be either constantly trying to engage different services or ceased engaging. No stable, supportive personal relationships.	Has some relationships with health providers but these may be dysfunctional in some aspects such as: a) ad hoc and disjointed; b) highly dependent; c) fearful and unwilling to ask questions. Personal relationships may be limited, have aspects of dysfunction (as above), or encourage unhealthful behaviours.	Has a trusting long-term relationship with at least one health care provider that they are confident enough to raise concerns and questions with. Some supportive family and friends. Able to negotiate ways to do the tasks and live the lifestyle necessary to maintain their health within their social contexts.	Moves in a social milieu that encourages healthful activities. Very strong trusting relationship with at least one health care provider who knows them well.



Version date: June 27, 2006

Figure 3: A determinants oriented model of health literacy⁹

As discussed previously, we consider determinants to be attributes of a person and/or their background, as well as external factors that have an impact on the ease and the extent to which people develop the capabilities that allow them to look after their health. They are often general rather than health-related characteristics or circumstances, and are often long-standing and difficult to modify. Many lists of such characteristics have been developed: the lists in Figure 3 relate to the narrower concept of health literacy (which can be considered a component of enablement). Some of the components that are listed as personal factors that influence health literacy should probably be considered as components of enablement (for example, personal health habits, some aspects of coping skills and other skills).

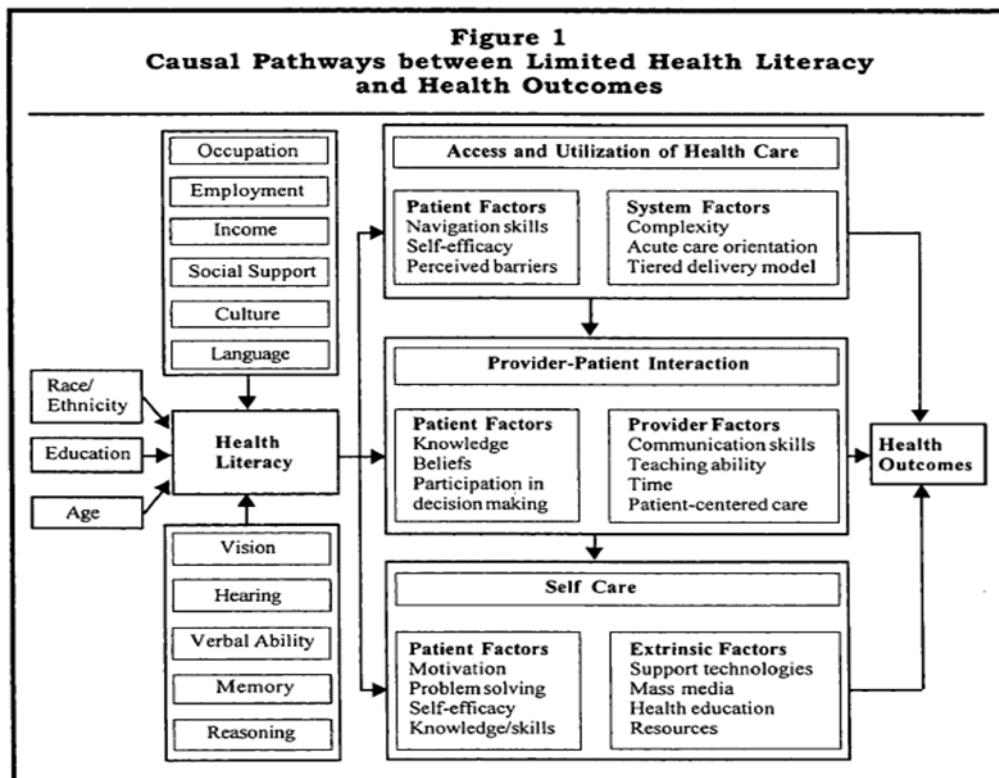
Outcomes of consumer enablement

Two conflicting views of potential outcomes of consumer enablement are apparent across policy and practice settings.

Within the public health policy and research sectors there is a tendency to adopt a normative perspective about the outcomes of consumer enablement. That is, an enabled consumer is one who follows the behaviours that those policy makers or researchers think are desirable. In this case the main indicator of enablement is compliance. 'Enabled' (compliant) consumers are therefore easier to manage, require less resources, and are the preferred client. A compliance-focused view of enablement is at odds with the priorities of consumers who tend to view enablement as related to choice and the ability to manage the impact of health issues on ones' life and aspirations.²⁻⁶

The ability to marry these two perspectives is critical: policy makers and funding bodies are required to demonstrate changes in enablement that are shown by evidence to produce real health and equity outcomes. At the same time, it is only when consumers see improvements in enablement as significant in enabling them to live their life in the manner that is meaningful to them, that these improvements are more likely to be sustained. Also, an understanding and willingness to engage with the life circumstances and aspirations of people in hard-to-reach and high risk groups will make it easier to engage these people.

The operationalisation of enablement is more complex when seeking to sustainably engage hard-to-reach and disadvantaged consumers, living in low resource environments. The first aim of interventions is often not to specifically achieve compliance with healthy behaviours, but to create environments where self-efficacy, self-management and agency (that is, the potential for ongoing enablement) become routine parts of the lives of people with low enablement. In these settings strategies need to support people moving to being as enabled as possible (that is, movement to the right of Table 3) and to prevent further decline in enablement (that is, movement to the left of Table 3), given their capability and contexts.



Source: Paasche-Orlow, M. K. and M. S. Wolf (2007). "The causal pathways linking health literacy to health outcomes." *Am J Health Behav* 31 Suppl 1: S19-26. ¹⁰

Figure 4: An outcomes oriented model of health literacy¹⁰

Figure 4 presents three categories of outcomes of the narrower concept of health literacy, but each of these is also a key outcome area for consumer enablement. These are:

- Access and use of health care
- Provider-patient interaction
- Self-care.

Note that in each of these areas the patient factors (components of enablement) are only partial determinants of outcomes. In each case there are additional extrinsic factors that determine if the patients' capabilities are adequate to their needs or not.

In moving beyond health literacy to the broader concept of enablement, it is necessary to consider two additional outcome areas:

- The ability of individuals to manage the impact of their health condition on their life and to integrate care of their health conditions with the demands of their life
- People's ability to advocate for issues that affect the health of themselves and their families.

Methods

Two rapid searches of the peer review literature and a grey literature search were conducted to generate evidence to answer the four review questions. The first rapid search was conducted to inform answers to all research questions, and the second was conducted to supplement the evidence for Question 1. A separate grey literature search, comprising 24 small searches was conducted to supplement the evidence for all questions. All searches were conducted in July 2016, the two academic literature searches were conducted in multiple research databases (CINAHL, PsycINFO, MEDLINE, Global Health, Health Source, Cochrane Library). The grey literature searches used Google Advanced and a range of key organisation websites. The search terms are presented in Tables 4, 5, 6 and 7, for rapid search 1, rapid search 2 and grey literature searches, respectively.

Rapid search 1

We included English-language systematic, peer-reviewed scoping and rapid reviews of systematic reviews investigating interventions for chronic disease self-management in adult populations, published after 2008. The reviews were excluded if:

- Disease-specific
- A narrative review
- The measurement outcome was too specific
- Intervention effectiveness was not evaluated
- Less than 10% of studies were published after 2006.

The search initially yielded 257 reviews/records, with 114 identified as being relevant to chronic disease self-management interventions. Of these, 61 reviews/records were chronic disease general (inclusive of all conditions), and 49 were disease specific (for example, diabetes). The abstracts of the 61 chronic disease general reviews were read to determine whether the reviews were systematic, scoping or rapid reviews. The review objective was to explore and determine the effectiveness of chronic disease self-management interventions. Twenty seven reviews met these criteria and were subsequently read in full. Four reviews were eventually excluded because they did not review the effectiveness of interventions. The reviews were assessed for inclusion by one reviewer, with a second reviewer checking a proportion of reviews for consistency. The quality of the reviews was assessed using the "A Measurement Tool to Assess Systematic Reviews" (AMSTAR tool).

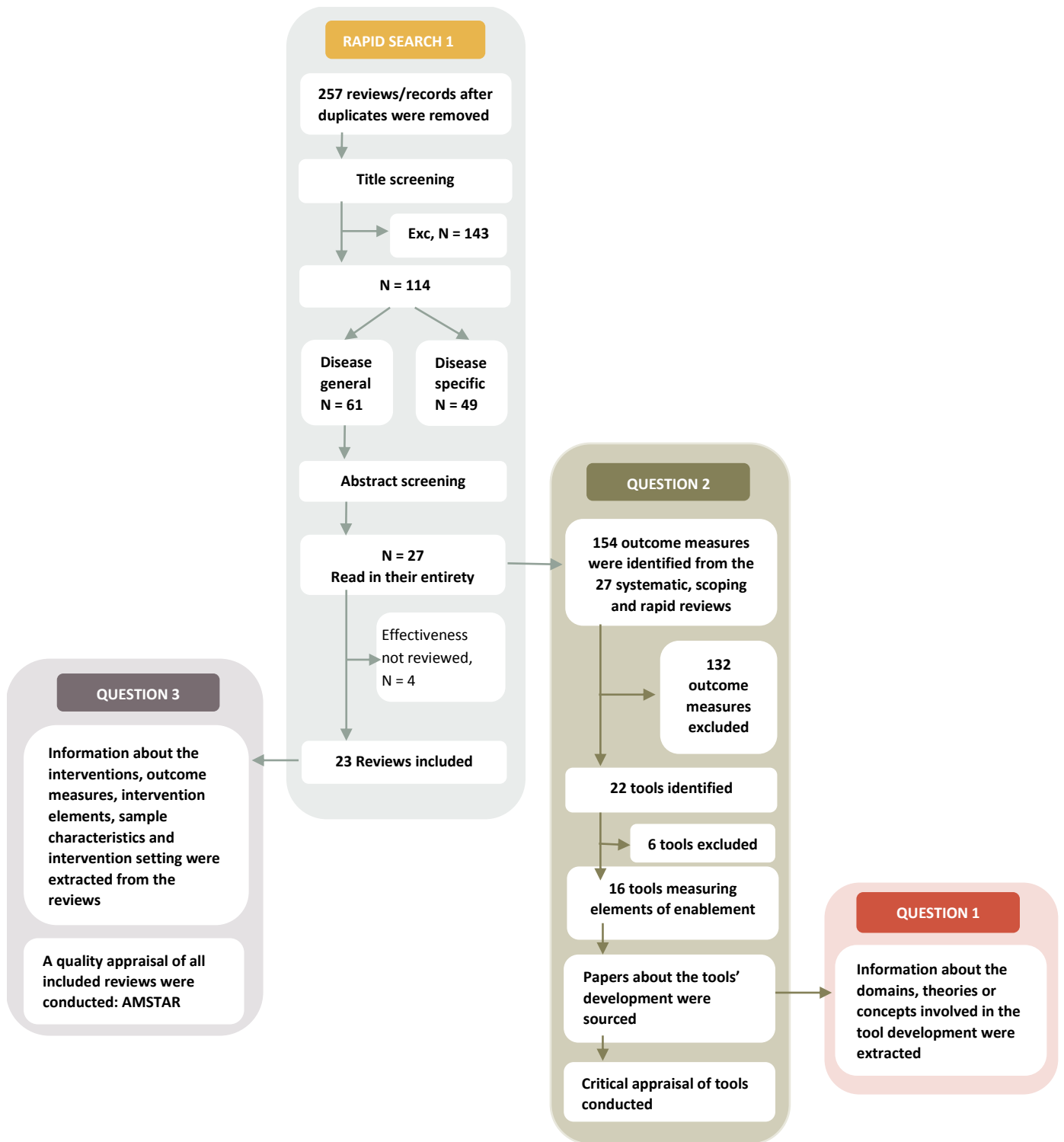


Figure 5: Search and retrieval process for the academic literature – search 1

Table 4: Search terms for rapid search 1

Term 1		Term 2		Term 3
"Systematic review" OR review	AND	"Chronic disease" OR "chronic condition" OR "chronic illness" OR "Long term condition"	AND	"self-management" OR "self management" OR "self care" OR "patient education" OR "patient empower*" OR "enable*" OR "Health literacy" OR "Health Knowledge" OR "Health skills" OR "Health comprehension" OR "health competence" OR "Health motivation" OR "self efficacy" OR "self-efficacy"

Rapid search 2

Rapid search 2 was conducted to identify English-language, peer reviewed, original articles published after 2006 investigating (1) chronic disease, (2) consumer enablement and related concepts, and (3) the determinants listed by the Agency of Clinical Innovation (see Section 0, p. 30). The search resulted in 988 studies once duplicates were removed. In order to increase the feasibility of the search, titles and abstracts were searched for the key terms: determinant OR risk factor OR causal OR protective factor OR predictor, which resulted in 116 studies. The abstracts of 116 studies were reviewed by one researcher who identified 42 studies that were likely to report on the relationships between 'determinants' and outcomes. These 42 studies were read in their entirety.

Table 5: Search terms for rapid search 2

Term 1		Term 2		Term 3
"Chronic disease" OR "chronic condition" OR "chronic illness" OR "Long term condition"	AND	"self management" OR "self-management" OR engagement OR "self-care" OR "self care" OR activation OR enable* OR Complian* OR Comply* OR Complied OR Adher* OR Noncompliant* OR Nonadher*	AND	Literacy OR "health literacy" OR "self-efficacy" OR "self efficacy" OR motivation OR knowledge OR navigation OR ethnicity OR cultural OR race OR language OR "socio-economic" OR "SES" OR "socio-economic" OR "social support" OR "social" OR "illness stage" OR "illness journey" OR "disease stage"

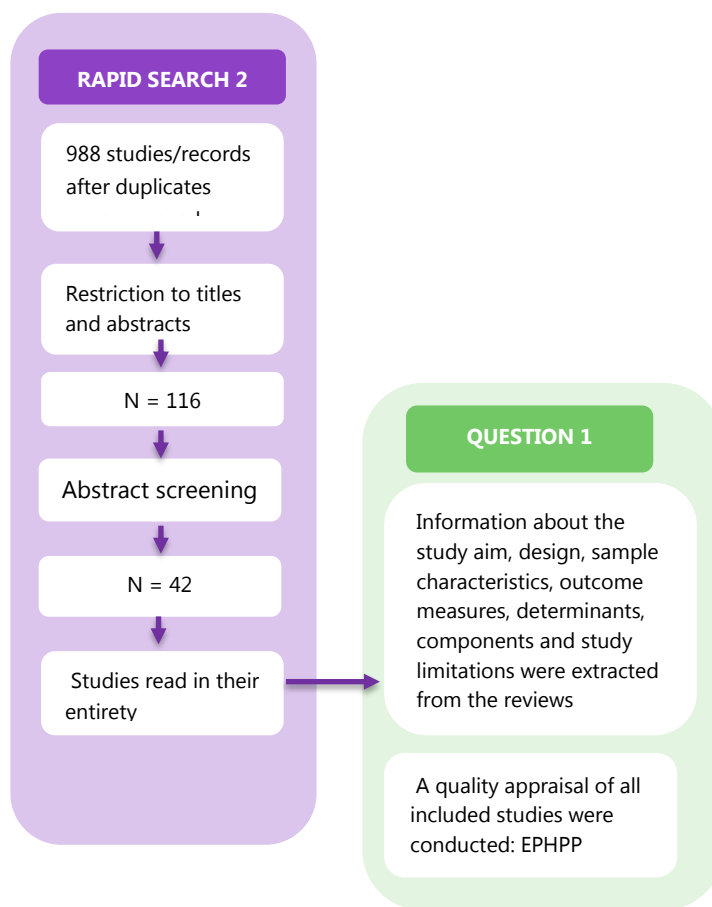


Figure 6: Search and retrieval process for the academic literature – search 2

Grey literature search

Although the academic literature is considered the gold standard in research, there are significant limitations associated with the academic literature, especially in regards to its representation of high risk low enablement groups and the clinical practices that have been developed to support them. In recognition of these limitations and gaps identified in the academic literature, a grey literature search was conducted to supplement the academic literature. The grey literature search was conducted systematically under the guidance of a Deakin University librarian.

Table 6 and Table 7 indicate key terms such as *chronic disease*, *enablement*, *self-management*, *health skills*, which were searched in Google advanced, as well as a search of the websites of key organizations such as the UK Health Foundation, NICE, WHO.

In relation to question one and three, 181 grey literature documents (including duplicates) were identified as relevant to the search. Specific to question two, 23 grey literature documents (including duplicates) were identified to be relevant to the search. See Attachment D for the full list of identified documents.

Table 6: Search terms for grey literature - Question 1 and 3

	Search terms, qualifiers, keywords, concepts	Limitations	Results	Included
Google advanced	"Chronic disease" "chronic illness" "self-management" "patient education" "patient empowerment" "Consumer enablement" "Health literacy" "Health Knowledge" "Health skills" "health competence" "Health motivation" "Tool" "instrument" "measurement" "Intervention"	English 2000 - present	697	47 of the first 100 were relevant to the search
Google advanced	Hospital risk minimisation program/s (or similar)	English 2000 - present	6,060	5 of the first 50 were relevant to the search
Google advanced	Patient activation and measurement (chronic disease)	English 2000 - present	2,680	4 of the first 50 were relevant to the search
Google advanced	clearinghouse + toolkit + chronic disease	English 2000 - present	135	7 of the first 50 were relevant to the search
Robert Wood Johnson Foundation - USA	chronic disease (enablement) (self-management) (health literacy) (health skills)	No limits	14	0 were relevant to the search
International organisation for migration	chronic disease (enablement) (self-management) (health literacy) (health skills)	No limits	20	0 were relevant to the search
International organisation for migration	chronic disease (enablement) (self-management) (health literacy) (health skills)	No limits	20	0 were relevant to the search
Health Foundation UK	chronic disease (enablement) (self-management) (health literacy) (health skills)	No limits	22	6 relevant to search.
Eurocare	chronic disease (enablement) (self-management) (health literacy) (health skills)	2000 to 2016	96	0 relevant to search.
Picker Institute	chronic disease (enablement) (self-management) (health literacy) (health skills)	no limits	2	2 relevant to search.
NICE	(chronic disease) (enablement)	2006-2016	166	18 relevant to search.
WHO	chronic disease (enablement) (self-management) (health literacy) (health skills)	2006-2016	213	8 relevant to search.
Agency for healthcare research and quality	chronic disease	2006-2016 (Australia only)	198	1 relevant to search.
Agency for healthcare research and quality	health literacy, empowerment, enablement, self-care	2006-2016 (Australia only)	241	6 relevant to search.
Google advanced	chronic disease self-management program evaluation	2006-2016 (any country)	35,900	13 of the first 100 were relevant to the search

Google advanced	chronic disease management program or TOOL "chronic disease"	no limits	13,400	18 of the first 100 were relevant to the search
Google advanced	patient enablement "chronic disease"	2006-2016 (any country)	3,440	20 of the first 100 were relevant to the search
Institute for healthcare improvement	chronic disease	2006-2016 (any country)	307	17 relevant to search.
Google advanced	"chronic and complex care" "determinants" "enablement" "chronic disease"	2000 to 2016	531	17 relevant to search.
Google advanced	social determinants and enablement	no limits	2,670	10 of the first 100 were relevant to the search

Table 7: Search terms for grey literature search Question 2

Site	Search terms, qualifiers, keywords, concepts	Limitations	Results	Included
Google advanced	Hospital risk minimisation program/s (or similar)	English 2000 - present	6,060	5 of the first 50 were relevant to the search
Google advanced	Patient activation and measurement (chronic disease)	English 2000 - present	2,680	4 of the first 50 were relevant to the search
Google advanced	clearinghouse + toolkit + chronic disease	English 2000 - present	135	7 of the first 50 were relevant to the search
Google advanced	toolkit or tool and "chronic disease"	English 2000 - present	1,850	7 of the first 70 were relevant to the search

Results of Evidence Check

This section presents the main results of the evidence check for each of the four main questions. The body of the report presents the main findings while details of the sources are presented in Attachments A and B. The scope for each question defined by ACI is reproduced at the start of the summary of results.

Question 1: What is the evidence regarding the determinants of consumer enablement in the chronic disease population and what implication does this have?

Scope of Question 1

The scope of this question defined by ACI is as follows:

- The population of interest for this review is people with chronic conditions. In this context, this includes those who currently have one or more chronic conditions, as well as those who are at risk of developing chronic conditions.
- Determinants of consumer enablement are defined here as sets of personal characteristics that make a person engaged. While the word “empowerment” refers more to the set of skills and resources involved in facilitating patients to take an active role in their own care, it is possible that literature about empowerment may also be relevant to answer this question.
 - Examples of determinants include, but are not limited to: literacy, health literacy, self-efficacy (defined as the strength of one’s belief in one’s own ability to complete tasks and take control of own health trajectory), motivation, knowledge, and one’s ability to navigate the health care system
 - Other characteristics of consumers that may influence enablement include: ethnicity, cultural background, language, socio-economic status, or social supports.
- Includes evidence regarding the role of the complexity of one’s condition in determining the level of enablement.
- The ACI is interested in health system and organisational factors that support consumer enablement, such as communication, interpersonal skills and clinical skills, as well as in patient information strategies. While not the main focus of the review, these should be flagged in a separate appendix using headings such as patient information, communication, and clinical skills.

Summary of findings from peer reviewed literature

The search resulted in 988 studies with duplicates removed. In order to increase the feasibility of the search, titles and abstracts were searched for the key terms: determinant OR risk factor OR causal OR protective factor OR predictor, which resulted in 116 studies. The abstracts of 116 studies were assessed for their relevance and likelihood of reporting findings about the relationship between determinants and outcomes that reflected engagement in chronic disease self-management, given that consumer enablement is not a commonly used term in research. 43 studies were reviewed, one of which was excluded because it did not cover a chronic disease¹¹ (see Figure 6 for the selection process). Our approach to identifying determinants was consistent with the World Health Organisation (WHO), which identifies structural determinants as: income, education, occupation, social class, gender, and ethnicity¹².

Two approaches were used to analyse the determinants of consumer enablement. First we considered a list of determinants identified by ACI in the specification of requirements for the evidence check. Secondly, we applied the framework of determinants, components and outcomes of consumer enablement that was presented in Figure 2.

Quality Appraisal

All studies were subjected to the Effective Public Health Practice Project (EPHPP) quality assessment tool¹³¹⁴. This appraisal tool has been used by the Cochrane Review group, and was selected based on its simple interpretation system (weak, moderate, and strong) and flexible application to different experimental studies. Limitations of the studies based on this quality assessment are presented in Table 14 in Attachment A.

Evidence related to determinants identified by ACI

Summary of results:

- Health Literacy: Four studies reported evidence to suggest that health literacy was related to outcomes that reflected engagement in chronic disease self-management, such as medication management capacity including ability to identify medication, patient's perceived barriers to participation, and ability to use online patient portals.^{15 16 17 18}
- Literacy: No studies from the rapid systematic search investigated literacy as a determinant of consumer enablement or related/constructs. The absence of recent literature investigating literacy as a determinant of consumer enablement and self-management behaviours may be a reflection of the differentiation between literacy and health literacy, as highlighted by the grey literature (Medibank PWC).¹⁹ Indeed, numeracy was considered a determinant in two of the black literature studies reporting on health literacy more broadly.^{16 18}
- Language: Only one study explored the relationship between language and consumer enablement-related concepts: patients who did not speak English were less likely to use resources for self-management.²⁰ Practical difficulties associated with recruiting non-English speaking participants may explain the low number of research studies. However, language barriers have been reported as an important consideration in the implementation of services and interventions.²¹
- Self-efficacy: Nine studies reported consistent evidence to suggest that self-efficacy was related to chronic disease self-management behaviours.^{22 23 24 25 26 27 28 29 30}
- Motivation: Four studies found a relationship between patients' outcome expectations and engagement with chronic disease self-management.^{31 32 29 33}
- Knowledge and/or beliefs: Seven studies reported evidence to suggest that knowledge and beliefs were consistently related to outcomes that reflected engagement in chronic disease self-management.^{32 34 35 36 37 38 39} These include beliefs and values about the disease and the treatment, benefit finding practices, religious commitment, and patient core values.
- Navigating the health care system: None of the studies from the rapid systematic search investigated service navigation as a determinant of consumer enablement or related/constructs.
- Ethnicity: Six studies explored and consistently found a relationship between ethnicity and outcomes that reflected engagement in chronic disease self-management.^{27 28 36 40 41 42} One of these studies found a relationship between ethnicity and patient-provider relationships in regard to program completion and concluded that increasing minority staff representation could increase level of elder minority participation.²⁸ A multi-morbidity study conducted in Scotland found that culturally appropriate educational programs improved knowledge and attitude for patients from different ethnic minority groups.⁴³ Another study specifically focused on Aboriginal and Torres Strait Islander populations with chronic diseases discussed enablement through the health practitioner's knowledge, skills and abilities.⁴⁴
- Socio-economic status: Eight studies found a relationship between age and outcomes that reflected engagement in chronic disease self-management.^{26 31 36 20 45 46 47 48} Seven found a relationship between education levels and outcomes in engagement in chronic disease self-management.^{36 40 20 30 17 49 50} Six found a relationship between income levels and engagement.^{36 40 41 30 51 52} Seven found a consistent relationship between gender and outcomes that reflected engagement in self-management.^{42, 45 17 53 50 51 48}, while two studies found a relationship with 'available socioeconomic resources' more broadly.^{33 51}
- Social support: Ten studies explored and consistently reported a relationship between social support and outcomes that reflected engagement in chronic disease self-management.^{25 53 50 51 54 55 32 34 38 45} One of these studies indicated that dependence on others was also negatively associated with engagement through an increase in depression.⁵⁵
- Complexity of one's condition: Five studies explored and consistently found a relationship between comorbidity and outcomes that reflected in engagement in chronic disease self-management.^{53 48 27 31 47} Three studies found a relationship between severity of illness and engagement.^{50 29 53}, two found a relationship with depression.^{50 31}, and another found a diagnosis of chronic schizophrenia related to engagement.²⁶
- Other: Other factors identified as related to self-management engagement include sense of coherence.^{26 25}, psychological status.^{53 27}, self-reported health.^{46 56}, generic quality of life.^{48 53}, empowerment.⁵⁰, Hba1c levels.⁴⁸, level of patient activation.¹⁷, number of medications.⁴⁷, number of hospitalisations.⁵³, mobility level.³¹, local environment.³¹, obesity.^{41 57}, and delivery system design and clinical information systems.⁴⁵

Based on the studies identified in this review, health literacy, self-efficacy, knowledge and beliefs, ethnicity, socioeconomic status, social support and illness complexity are determinants of consumer enablement supported by multiple studies with consistent findings. Other determinants such as language, motivation,

psychological status and health service provision were also identified in the literature: however, less evidence supported them as determinants of enablement.

It is worth noting that less evidence in these studies does not imply that these are not important determinants. Given that there has not been a focused program of work that sought to explore determinants of enablement, the identified studies generally reflect incidental research in the area. Some studies explored a narrow set of potential determinants of enablement. Indeed, we have sought to differentiate the skills, cognitive states, affective states and physical capabilities that we consider make up enablement for health behaviours, and external determinants of enablement.

Applying the framework for enablement: determinants, components and outcomes

One of the main difficulties in analysing the empirical literature is that it is unclear whether consumer enablement should be identified with: a) the outcome variables (in most cases specific target behaviours as desired by health providers), or b) with the independent variables (health literacy, self-efficacy etc.). Treating outcome variables as targeted health behaviours as a proxy for enablement reduces enablement to compliance rather than a set of abilities. In fact people may be browbeaten into compliance in a way that actually diminishes their sense of personal control, self-trust, trust in providers, skills in reflecting on health information and many other key elements of enablement.

An alternative is to treat many of the independent variables as **components** of enablement in a causal sense. In this case, health literacy, self-efficacy, motivation, some health service navigation skills would be considered to be aspects of what it means for a person to be enabled. Part of this confusion lies with the fact that terms like enablement tend to have very fluid meanings and can be used in different ways at different times and receive different emphases from different stakeholder groups. We thus distinguish between determinants, components, and outcomes.

Determinants are at the more general level and include, for example, general confidence, general education, level of stress, or level of fitness or fatigue (as outlined in the Introduction).

Components are the aspects of a person or group of persons that have a direct effect on their ability to care for their health and/or manage the impact of health issues in their lives.

Importantly for this distinction, components are more specifically related to health and health related decisions and **are potentially modifiable in the short to medium term**. They include, for example, confidence in accessing health services to make specific lifestyle changes, or knowledge to find information on specific health needs.

We consider that there are **three categories of determinants**:

1. Individual (personal): factors relating to the individual's cognition, emotional states, habits and physical abilities that have an impact upon their ability to be engaged in caring for their health, as well as specific knowledge and skills relating to health enhancing activities and behaviours.
2. Dynamic (experiences with health care): factors relating to current user friendliness of the health care system and the person's current level of relationships and engagement in the health system as well as past experiences.
3. External (factors in the social and physical environment): factors relating to the family and community environment in which a person lives and works. External factors also include structural determinants such as socio-economic status and the health services that are available for people to access.

Through applying this categorisation to the literature on determinants, it is apparent that some determinants have received different levels of attention. All but four studies investigated one or more individual (personal) determinants, such as health literacy¹, beliefs and knowledge, and physical mobility.^{20 36 39 58} All but four studies investigated one or more external factors relating to the patients social or physical environment such as age, gender, income, education.^{59 60 15 24} However, of the 38 studies that did

¹ Health literacy, as it is currently conceptualised, is as broad and fluid a concept as enablement, and is often considered to be a dynamic characteristic involving the interaction of an individual's characteristics with the characteristics of the health system. The studies cited, however, used tools to measure health literacy that encompassed a more basic understanding in terms of the ability to apply literacy and numeracy skills to certain health tasks, therefore health literacy is classified as an individual, largely cognitive determinant.

investigate at least one external factor, only one study considered language and non-English speaking as a determinant for investigation.²⁰ Thirteen studies investigated a determinant related to patient experiences with health care.^{58 37 61 23 39 40 45 28 17 46 52 51 55} Eleven studies examined at least one determinant from each of the three categories.^{46 52 51 55 37 61 23 40 45 28 17}

Details of these studies and evidence of the association between the determinants and components of enablement or, more often, the association between the determinants and outcomes of enablement (with no intervening measure of the components of enablement), are presented in Table 13 in Attachment A. Limitations of the studies based on the quality assessment are presented in the Table 14 also in Attachment A.

We also considered the studies in relation to three levels of enablement:

- **Highly enabled** – can self-refer and are highly aware of their health state and can initiate actions as they require
- **Moderately enabled** – require some prompting, reminding and assistance
- **Low enablement** – have major gaps in enablement capacity and particular barriers that make caring for their health difficult particularly for those having special needs requirements.

Applying these enablement levels to the evidence in the literature on determinants indicates that most studies have focused on patient cohorts that are of moderate to high enablement. This indicates a potential gap in the literature for the determinants of engagement for those with special needs.

Components of consumer enablement

As outlined in Figure 2 and Table 3 we conceptualise **four categories of components of consumer enablement**. Findings from the determinants literature are arranged according to these categories:

1. Cognitive components

From our analysis of the determinants literature, evidence of cognitive components that are both related to and outcomes for consumer enablement, include cognition⁵³ and knowledge and beliefs about treatment^{37 35}.

2. Affective/motivational components

Evidence of affective/motivational components that are related to outcomes for engagement in chronic disease self-management programs include psychological status²⁷, feelings of aversion towards medication^{34 35}, patient alterations to medication regime³⁴, benefit finding³⁸, frequency of self-care activities³⁸, level of self-confidence in controlling disease³⁵, action and coping planning²⁹, perceived barriers²⁹, outcome expectancy²⁹, and motivation to adhere.³³

3. Physical components

Physical components that have been found to be related to outcomes for engagement include mobility level³¹, problems with medication side effects^{35 34 22}, physical impairments and limitations.

4. Relational components

Evidence on relational components that affect enablement include family and friend support^{53 34 54 55 38 25 51}, relationship type^{53 25}, perceived loneliness^{54 55}, confidence in one's physician³⁷, provider-client relationship^{28 58 17}, providers' provision of information⁶¹, providers' efforts to involve patients in decision making⁶¹, community linkages⁴⁵, level of disease-specific support⁴⁸, and provider specific health training.⁵⁷

Finally, **outcomes** are not simply changes in health status, but refer to access and use of health care, provider-patient interaction, self-care, ability to manage the impact of health conditions on life and integrate care into daily life, and ability to advocate for issues that affect the health of consumers and their families. Outcomes examined in the determinants studies include seven studies on medication adherence^{58 34 37 61 35 60 24}, nine on self-management broadly^{53 25 61 26 29 30 16 33 51}, six on self-care^{53 61 27 50 40 52}, as well as studies on ability to meet physical activity requirements^{22 31}, health-promoting behaviours^{30 49}, patient activation^{46 56} more broadly, improvement in health status²³ and more.

Strategies to influence the determinants of consumer enablement

Many of the peer reviewed papers analysed in the evidence check for Question 1 also contained evidence of direct relevance to Question 3. Some of the studies were trials of specific interventions, but these were not usually interventions targeted directly at consumers, as is the case for most of the interventions explored in Question 3. Instead they attempted to influence health system and organisational factors that support consumer enablement, such as communication, clinical skills, culturally appropriate information, as well as

social support strategies, that is, they attempted to influence various determinants of enablement. Details of these studies are included in Table 13 in Attachment A. The summary findings are:

- **Culturally appropriate resources:** One study investigating resource utilisation recommended providing culturally appropriate resources and training for staff so that caring partnerships could be developed between patient and health care provider.²⁰ Another study in Canada found that patients need 'self-care education consistent with their cultural beliefs' and that for Aboriginal patients in particular, 'nurses need education on Aboriginal beliefs and practices'.²⁷ A US study examining patient provider relationships found that increasing minority staff representation could increase elder minority participation.²⁸ Another US study found that despite efforts to make a program culturally sensitive, those less educated were less likely to participate and that cultural background was still a determinant in those failing to complete baseline assessment after initially agreeing.¹⁶
- **Education/patient information:** One study on patient knowledge of medical insurance recommended government agencies enhance education programs³⁶, another study on participation in physical activity programs found a strong need for education²², as did a study on patient-provider communication.⁶¹ One study emphasised the need for nurses to provide education for self-care management²⁵, a study on motivation also found that education on physical activity benefits may enhance outcomes related to self-management.²⁹ The provision of specific health information for inmates was also recommended by researchers of inmate health³⁰, and four other studies highlighted the importance of providing easily accessible health information.^{53 33 18 31}
- **Clinical Skills:** One study found that clinicians' access to resources was related to patient self-care, where better access to resources transferred to knowledge in patient self-care activities⁴⁵: "clinics with teams that have well-defined leadership and effective teamwork, where the appointments and visits' systems are well structured and where follow-up and coordination of care after the visit are well planned, seem to have an advantage in terms of controlling CV [cardiovascular] risk factors for their diabetic patients". Another study emphasised the important of health professionals equipping patients with skills.³⁸ One study highlighted that the role of multimorbidity needs to be reflected in clinical guidance, training and improvement initiatives⁴⁷, while another urged incorporation of disease-specific risk management into routine mental health training for practitioners.⁵⁷
- **Social support:** Two studies highlighted the key role of nurses in providing emotional support to patients.^{38 25} Another study recommended peer volunteer-mentor groups, service outreach, facilitated transportation for homebound patients and the provision of in home services as mechanisms that improve social support and engagement in self-care management.⁵⁴ One study found that health mentor programs enhance consumer completion of a program²⁸, while another recommended that organisations facilitate relations with providers and between patients on similar regimes to improve engagement.³⁷ Another study recommended the involvement of pastoral counsellors or psychotherapists to address social isolation, a determinant of enablement.³⁹
- **Participation:** One study found a linkage between patients' trust in their provider and the provider's ability to integrate patient experiences in their self-management plan⁶¹, while two others emphasised the need for health providers to align care plans with patient values³², by negotiating agendas with patients early.¹⁷ Another determined income as a key issue for access to participation.³³
- **Communication:** One study recommended enhancing communication efficacy in interventions to improve outcomes.¹⁷

The grey literature provided a broader perspective on determinants of enablement, particularly around consumers being supported to make decisions.

Consumer perspectives that make people feel more capable in making decisions and taking actions (feel enabled / motivated).

Starfield⁶² explored the personal meaning of illness through being sensitive to patients' preferences for information and education, and sharing power and responsibility. This makes the patient feel empowered. Understanding the issue from the patient perspective and comparing this perspective with the problems as recorded by the practitioner has been shown to facilitate patient empowerment.

Giving specific information that supports choice and consideration of options is important for people to make up their own minds about participation in interventions and use of services.⁶³

Patient activation includes encouraging patients to be aware of their role in condition management including the skills, knowledge and confidence they need to manage their illness.⁶⁴

From the consumer perspective, improving outcomes can be facilitated through the notion of a “no wrong door” patient pathway: this can be aided through an integrated and coordinated system.⁶⁵ This approach can help decrease inappropriate referrals and lost time to the patient while improving patient confidence.

At the individual level, many strategies and programs have been used to put the patient in control of their own health through keeping healthy, shared decision making, structured self-management, having a personal health or social care budget, involving families and carers, choice of provider, taking part in research of condition and treatment (see Kings Fund “People in control of their own health and care: the state of involvement”, Catherine Foot et al.).⁶⁶ Evidence suggests more empowered patients (supported with health information, self-management resources and skills and patient ‘activation’ programs) are more likely to have the skills knowledge and confidence to articulate their needs.⁶⁵

Patients with chronic diseases have highlighted the importance of a support network (family and friends) assisting the healthcare team in co-ordinating care, goals and treatment.⁶⁷ Allowing them to be present at appointments assists absorption of information and asking questions. In addition, patients networking with other people who are in a similar situation has been effective in allowing patients to learn about management strategies.⁶⁷

A Scottish study aimed at understanding the experiences of what worked and didn’t work for people with dementia found participants felt that:

“...people actually accepted us for who we were. They didn’t try to change us, they didn’t try to make us get better quicker, they allowed us to get comfortable in our own time and then once you got your voice you were encouraged to go out there and say it when you were comfortable with it. I think because we accept each other, we learn to accept ourselves.”⁶⁸

Components / determinants that have been identified as important to people with low enablement or specific target groups

- In Australia where one in five people speak a language other than English at home, linguistically and culturally appropriate prevention and management programs for people with chronic disease are essential to enable all groups to get access to programs.⁶⁹ This requires an ongoing process of evaluating culturally appropriate targeted information and services. Enhancing empowerment for culturally and linguistically diverse (CALD) communities is aided by the use of pictures and diagrams as well as translations of common terms.⁷⁰
- Older people in these communities may have specific learning needs and are likely to have less knowledge about self-care, potentially putting them at risk of poorer outcomes.⁷⁰
- A study with Somali women found favourable health care experiences included: effective verbal and non-verbal communication, feeling valued and understood, availability of female interpreters and clinicians, and sensitivity to privacy for gynaecological concerns.⁷⁰ Other factors thought to be prerequisites of a health care system that seriously sought to engage their needs included; access to adequate transportation, physical access to healthcare services and community-based programs to improve health literacy about women’s preventive health services.⁷⁰
- When engaging with vulnerable groups, interpersonal communication based on trust, understanding, empathy and cooperation between the patient and the health practitioner is essential. This involves both verbal and nonverbal communication and the tailoring of messages to the needs and preferences of the patient through appropriate educative strategies to clarify meaning and intent.⁷¹
- For many patients from vulnerable groups, “regardless of how great the care is, you really need someone by your side 24/7. That care partner thing could be really great because my husband really knows me (patient quote)”.⁷² Health services committed to being responsive to consumers’ needs and expectations recognise the invaluable support role of family and friends. Patient-centred organisations welcome family members, not only by lifting many of the restrictions that have historically limited their involvement, but also by actively encouraging their participation as members of the care team.⁷²
- Older adults have been shown to have greater satisfaction with care in their home/community to treat less serious conditions.⁶³ Older adults from *lower socio-economic groups* are at higher risk of avoidable emergency admissions where health outcomes depend on the *quality of service* rather than where it is provided.⁶³

Conclusions

Much of the academic literature on determinants of enablement and the effects of enablement on outcomes relates to people with moderate to high enablement. An extensive number of determinants of enablement that relate to sociodemographic characteristics, consumer skills, health problems and the nature of health services were identified. There was more content related to the needs of people with low enablement and/or special needs in the grey literature. This gave particular prominence to relational aspects of enablement, including how health providers manage their relationship with the consumer and the need to engage families and communities.

Both the interventions considered in this section, which were mostly focused at the level of health providers and community or health organizations, and the qualitative and experiential evidence from the grey literature, highlight that enablement is usually determined by an interaction between individual characteristics and the characteristics of health services and the communities in which they live. For example:

- Individual language skills, knowledge of health concepts, cultural views and preferences interact with the quality, clarity and cultural relevance of information provided by health services to determine a person's ability to understand and act on health information
- A person's general level of self-confidence and self-efficacy (affected by their educational, knowledge and life experience) interacts with the approachability of health service providers and their willingness to listen and negotiate, to determine a person's ability to meet their health-care needs
- A person's level of physical ability or disability interacts with the availability of suitable exercise facilities within in the community along with societal attitudes to seeing people with physical limitations
- A person's access to transport and money interacts with the availability of transport, health services and opportunities to participate in health-enhancing activities that are provided in a community.

Within any of these interactions, negative experiences can undermine a person's future confidence and thus their ability to attempt and achieve health enhancing activities, while positive experiences can build their confidence. These positive and negative experiences can occur at both an emotional and practical level.

Positive and negative experiences at the emotional level: Positive influences identified at the emotional level include health providers' sensitivity, openness to questions, willingness to negotiate and proactivity in eliciting consumer perspectives. These are major factors in determining the trust and credibility people give to those health providers and the advice they receive. Negative experiences at the emotional level include experiences of feeling stigmatised, judged or in conflict: these feelings undermine peoples' willingness and ability to interact with others or to put themselves into situations where they feel exposed to judgement.

Positive and negative experiences at the practical level: Positive practical experiences occur when people receive information and advice that fits in with their priorities, takes account of their views, and is practical and actionable. Practical influences also include the provision of 'no-wrong-door' processes for accessing health services and the availability of people to help them effectively navigate health services. They also include the availability of problem-solving support where people hit difficulties in health activities like physical activity, health eating, self-monitoring and using medications, as well as the availability of resources in the community that support health enhancing activities such as exercise opportunities, healthy fast food, transport, affordable healthcare and supportive social groups.

The need to focus on both individual and social determinants:

There is sometimes a tendency to consider those who are highly autonomous in all the activities considered above as 'highly enabled' and to consider this a virtue. However, everyone has limits in what they can do on their own. A person who has a highly autonomous style may hit crisis situations in which their capacities are exceeded and their lack of established support structures becomes problematic. Also, an emphasis solely on the individual aspects of enablement fails to recognise that many people and cultures have a more interactive style in the way they manage their health and in what enables them to do so effectively.

There is also a need for a long-term, interactional focus when we consider how to influence the determinants of enablement. While there is value in some short-term activities aimed at enhancing individual abilities—such as various activities to increase health knowledge, change health beliefs, develop life skills, improve consultation skills, orient people to health services, assist people to distinguish between good and poor information, and build supportive social networks (see also Question 3)—it is necessary to recognise that enablement is largely determined by long-term experiential learning as people care for their health, and the health of those they are responsible for, through the life course.

Question 2: What tools and instruments have been shown to be valid and reliable and clinically useful, for which groups, in measuring the drivers and components of consumer enablement?

Scope of Question 2

- Examples of tools we would like included:
 - Health literacy questionnaires: Rapid Estimate of Adult Literacy in Medicine (REALM), Test of Functional Health Literacy in Adults (TOFHLA)
 - Ophelia (OPTimising HHealth LIteracy and Access to health information and services)
 - Patient Activation Measure (PAM), Self-Efficacy for Chronic Illness Tool
 - Behavioural questionnaires: The Readiness Ruler, Beliefs and Behaviour Questionnaire (BBQ), Readiness to change questionnaire
 - Patient Empowerment Scale (PES), Empowering Speech Practices Scale (ESPS), Patient Enablement and Satisfaction Survey (PESS)
 - Patient Health Engagement (PHE) Scale, Partners in Health Scale (PIH).
- Some tools (such as REALM) measure determinants of enablement as well as enablement itself. Both are relevant to the ACI since the ability to measure different components of the system is central to the Framework for consumer enablement.
- The ACI is particularly interested in tools that have been implemented in the field, especially those that are easy to use and do not require license fees. Long survey instruments that have not been fully tested, validated and implemented might be cited, but are of marginal relevance to this review.
- The ACI is particularly interested in knowing:
 - What tools are available
 - What is being measured and in what context
 - Which tools measure across multiple determinants of consumer enablement
 - For which population is the tool designed and for which patients are the tools most effective.
 - Whether there are gaps in the type of tools available? The answer to this question should go into a special section “Gaps Analysis” (see section “Depth and scope of the review” below).

Summary of findings and recommendations

Optimal enablement of consumer participation in the management of their healthcare requires:

- Knowing the enablement status of consumers, and then
- Applying appropriate supports and interventions (sensitive to their enablement status)
- Determining whether enablement was optimised across all members of the community.

Consequently, the key places where measurement is required are: a) needs assessment that supports decision-making about what interventions to provide, b) quality assessment and monitoring, and c) outcomes measurement.

In thinking about these functions it is necessary to consider the potential application of the tool with **individuals** and with **groups**. Different criteria for validity and usefulness need to be applied when judging the suitability of tools for application at the individual and group level.

At the group level the key criteria include statistical psychometric validation, concept coverage, ability to measure across a range of levels of enablement, and sensitivity to change. These criteria are discussed in detail in the review of the individual tools in Attachment B.

Table 8 List of questionnaires appraised for utility in measuring enablement

1.	Patient Activation Measure (PAM)
2.	Beliefs and Behaviour Questionnaire (BBQ)
3.	Test of Functional Health Literacy in Adults (TOFHLA)
4.	Health Literacy Questionnaire (HLQ)
5.	Health Education Impact Questionnaire (heiQ)
6.	Chronic Disease Self-Efficacy Scales (CDSSES)
7.	Patient Health Engagement Scales (PHE)
8.	Health Distress Scale (HDS)
9.	University of Rhode Island Change Assessment Questionnaire (URICA)
10.	Rapid Estimate of Adult Literacy in Medicine (REALM)
11.	Empowering Speech Practices Scale (ESPS)
12.	Patient Empowerment Scale (PES)
13.	Patient Enablement Instrument (PEI)
14.	Patient Enablement Satisfaction Survey (PESS)
15.	Partners in Health Scale (PIH)
16.	Patient Assessment of Chronic Illness Care (PACIC)

Using tools for assessment of individuals

At the individual level it is necessary to consider three different ways in which tools are used in the decision-making process:

1. The tool is scored and the score is used to direct people into different streams or types of service delivery
2. The tool is used as a checklist to ensure that clinicians consider multiple aspects of enablement in the formulation of their intervention plan. This decision-making process should be based on the content of the answers to the different questions rather than an overall score
3. The tool is used as part of a structured participatory decision making process involving discussion and negotiation between the health provider and the consumer.

A fourth possible model combines one and two above. In this model a tool that has multiple scales covering different aspects of enablement is used to create a profile of strengths and weaknesses. This profile, rather than a single score, informs the clinician's thinking and decision making. This model could also include the third approach if the profile is used as the basis for discussion with the consumer.

The validity and utility criteria for the use of measurement tools for each of these purposes are different.

Table 9: Critical appraisal and recommendations for tools to assess individual enablement

Type of use	Validity and utility criteria	Tools
Score guides allocation	Strong statistical, psychometric properties including item response analysis and Rasch analysis. High predictive validity (correctly allocates people). Adequate concept coverage. Can be quickly and routinely applied. Sensitive across high to low enablement	None. The PAM has the most research behind it in this direction but falls short as discussed in Attachment B. PHE is promising but the specific content is also valuable especially for low enablement groups.
Checklist guiding clinicians	Coverage of concepts that are important to both the clinician and the consumer. Questions understood in the same way by clinician and consumer. Information leads to decisions that are satisfying to both.	BBQ, HLQ*, heiQ*, HDS**, ESPS, PHE
Discussion tool. Aid to participatory processes	Coverage of concepts that are important to both the clinician and the consumer. Questions understood in the same way by clinician and consumer. Information leads to discussions that are satisfying to both, to greater mutual understanding and enable a consensus on goals.	The PIH was specifically developed for this purpose and has the strongest evidence#.

* Produces a profile of scale scores

While not reported here, the Conversational Health Literacy Assessment Tool (CHAT), based on the HLQ, is designed to be incorporated into normal clinical interviews and is freely available. CHAT is in the final stages of validation.

** Some tools measure a single aspect of enablement that can be important for clinicians to consider.

A number of tools sit in an uncomfortable place somewhere between the first and second forms of use. For example, the content of the PAM, the TOFHLA and especially the PES may be very useful to guide clinician decision-making, but the statistical psychometric basis for the scores and the meaningfulness of the scores is dubious, and there is no evidence for their ability to predict future needs at the individual level. Also a lot of information is lost in reducing the answers to a broad range of questions to a single score.

Just as there are dangers in trying to apply tools that were developed and validated to assess differences and needs in groups to decision-making processes with individuals, the reverse is also true. Tools that are effective aids to decision-making processes with individuals may not have the properties necessary to distinguish between groups or to measure change.

Summary of promising group assessment tools

To gauge the potential for an identified questionnaire to capture enablement, the scales were critically appraised and classified according to their coverage of one or more of the levels of enablement capacity. Questionnaires were classified as covering: i) physical capacity, ii) cognitive capacity, iii) motivational capacity, and iv) relational capacity. Judgements were then made about reliability and validity, followed by the practicality of each questionnaire regarding length, and level of enablement captured (mainly whether evidence suggests it can measure low enablement).

Enablement is clearly a multi-dimensional concept, and no multi-dimensional tool has been developed that has sought to comprehensively measure the breadth of the enablement concept. Several tools have been developed that measure specific elements of the enablement concepts.

Application of tools at the group level include three main functions:

- Needs assessment
- Practitioner and service quality monitoring
- Outcomes assessment.

16 tools were identified in the literature. However, following critical appraisal, most of these were excluded due to inadequate measurement properties or poor targeting to the enablement concepts.

Recommended group assessment tools

1. Needs assessment – tools that identify enablement strengths and limitations of individuals and groups

Only one tool was identified that functions as a formal needs assessment and taps into elements of enablement - the Health Literacy Questionnaire (HLQ). It comprises nine independent questionnaires (each with 4 to 6 items) that cover three elements of enablement. It does not cover Physical capacity. It provides a profile of strengths and weaknesses designed to inform service providers. While not designed for assessment of individual level (patient) needs assessment, preliminary research suggests that some scales are suitable for this purpose.

The HLQ has been used in several settings as a needs assessment tool, and practitioners and managers have found the data to have high utility. A profile of relative weaknesses (needs that need to be strengthened) and relative strengths (that can be built on and leveraged, and that may compensate for a range of other weaknesses) assists practitioners, managers and regional planners to develop co-ordinated strategies. These data can inform service providers of the particular needs of groups of clients so they can tailor program content and structure to best support clients.

2. Practitioner and service quality monitoring

- a. The Patient Assessment of Chronic Illness Care (PACIC) assesses in detail relational enablement, that is the client perspective of the quality of client-practitioner interactions in primary care. Designed to inform service quality in relation to the Chronic Care Model.
- b. The Partners in Health (PIH) scale, while designed to support and improve patient-clinician interactions, may have a role in evaluation of service delivery quality.
- c. The Health Literacy Questionnaire (HLQ), covering three of the four enablement dimensions, reflects a range of determinants from quality of information provided, how navigable the services are, and how supportive the services and their social network are. Specific enablement determinants could be selected from among the dimensions, given local context and service development and improvement goals.

The above tools can be applied in specific parts of the health system to monitor quality. This has been demonstrated with profile tools such as the heiQ. For example, the Expert Patients Program Community Interest Company (EPPCIC - formally the EPP, a national initiative of NHS England) have built a software system to monitor the quality and impact of a diverse range of chronic disease self-management programs. See Self-Management-UK <http://selfmanagementuk.org>. A similar approach could be followed in Australia through routine collection of pre-post enablement data (for example, HLQ, PACIC), which could be entered into a web system so that practitioners and managers would be provided with prompt and benchmarked data to inform them of current practice quality. Such a system could monitor changes over time. Such a system could be an effective (proximal) outcomes measurement system, providing information to program managers on the impact of various programs.

3. Outcomes assessment

- a. While the heiQ has license fees, it was the only tool specifically designed to measure proximal outcome of chronic disease self-management services. It's eight independent scales have good coverage of enablement, but not physical capability.
- b. The HLQ measures a number of issues that are often key intermediate outcomes in enablement interventions, such as confidence in accessing and using information to make decisions and confidence in engaging with health providers and services. It doesn't, however, capture physical capability.

A valuable aspect of systematic or selective pre-post service evaluation is the opportunity to map both the baseline status of clients and the magnitude of benefits that various clinical and demographic groups receive. Baseline data can inform managers about whether people with low enablement are actually being engaged and included in services. The collection of follow-up data can then inform managers and service providers of the relative benefit specific client groups are receiving. This is most powerful when wide area data are in the system and norms or benchmarks are available.

Promising tools that do not meet all preferred requirements

The Patient Activation Measure (PAM) was excluded because as it is a proprietary tool, it has had very limited use in Australia, and because of doubts about its ability to measure low levels of enablement related to concerns about the scoring algorithm.

Test of Functional Health Literacy in Adults (TOFHLA) and Rapid Estimate of Adult Literacy in Medicine (REALM) were excluded because they have had limited application in Australia, tap into a narrow part of the enablement concept (cognitive, especially reading/numeracy, i.e., functional health literacy), are cumbersome to administer (require interviewer), have poor construct validity (REALM), have scores generated by a USA-based educational scoring algorithm which has unknown relevance in Australia, and have potential for stigmatisation of people with low literacy/low enablement.

The Partners in Health (PIH) scale was excluded for most applications because it has had limited psychometric testing, and was designed as a tool to optimise introduction of self-management to patients during clinician-patient consultations.

Health Education Impact Questionnaire (heiQ) may be considered as being too lengthy, but has positive properties such as very good psychometric properties, extensive testing in Australia, and ability to measure enablement-like outcomes. Given that it comprises eight separate and relevant questionnaires, specific questionnaires could be selected to cover different elements of enablement given the particular population being studied.

Several other tools, while identified as measuring elements of enablement, were regarded as not suitable or promising as they were underdeveloped, impractical, excessively narrow given the number of questions, likely to be insensitive to low levels of enablement, or were specific to a clinical discipline and would require significant redevelopment for generic use.

Gaps in the measurement of enablement

There are few measures of a key element of enablement, physical capability. Table 3, suggested that, people with low physical components of enablement are: *Severely limited in their ability to undertake self care and basic health care tasks or participate in any health promoting activities* while people with medium levels are: *Physically capable of doing most self care and health care tasks independently though may need some assistance with transport. Limited ability to achieve physical activity levels necessary to maintain or improve their health.* Recognition of physical factors affecting enablement is important, as early recognition, and putting supports in place, provides opportunities for virtuous cycles: that is, as people with low enablement experience positive changes in relation to physical issues, other levels of enablement are likely to strengthen, potentially building further physical capacity and further protection from loss of health and wellbeing. Conversely, loss of physical capacity may lead to a vicious cycle, with the loss of cognitive, motivational and relational capacity.

There is a gap regarding proof of the 'clinical utility' of measurement tools. The generation of this type of evidence at the individual patient level is rarely undertaken systematically. Furthermore, measures need to have much stronger psychometric properties to make individual patient level decisions. This requires high reliability scores, which are often generated by incorporating a large number of questionnaire items, which then make tools impractical at the clinical practice level.

Approach to the review of measures of enablement

Development and validation of questionnaires is often poorly done. Some tools may have been based on excellent clinical and system insights and then weak psychometric development and testing processes are applied. In contrast, other tools may have been developed using well-described theory (recent/popular or well established) and strong measurement science, but attempts to operationalise them into real world settings ignore incongruences between theory and practice. Many research and/or clinical groups enthusiastically engage in validation studies and do so without a robust understanding of measurement science, leading to a raft of studies that are hard to unpack and, at times, based on false premises. Many authors enthusiastically overstate claims, without fully considering of the veracity of the evidence that they are presenting. Consequently, for most questionnaires, the evidence is patchy.

Validation is a process that occurs over time and involves developing a web of evidence demonstrating that the tool is fit-for-purpose and that the data it generates can reliably and validly be used to make decisions about individuals, groups, programs and policy. Few developers work through this process. Many tool developers are simply unaware that it is not the 'tool' that is validated, it is the interpretations and applications of data generated that is validated (or proven) in order to make appropriate decisions in specific contexts. This process is fundamental to key international guidelines for questionnaire development and validation⁷³, which we call a validity-driven approach.⁷⁴

In seeking to make judgements about Question 2 we have followed the following steps where possible:

1. Systematically identify tools that claim to, or appear to, measure elements of enablement.
2. Identify the source manuscript where the tool was initially published and outline the nature and quality of its development process.
3. Use citation search function to identify papers citing the original paper to locate subsequent validation and application papers.
4. Review studies undertaken in relevant contexts in Australia.
5. Map the constructs of the tool to the four components of enablement, with summative judgements about the utility of the tool's scales. Where possible, make a judgement about whether scales tap into low levels of enablement.
6. Make an overall recommendation, if possible, given the available evidence.

Note that a recently published systematic review of enablement questionnaires⁷⁵ identified only two questionnaires from 53 identified questionnaires potentially assessing enablement in clinical practice. The two questionnaires identified were the Empowering Speech Practices Scale (ESPS) and the Patient Empowerment Scale (PES) (both included in the 16 we identified for detailed review).

Question 3: What does the evidence show in relation to specific interventions that support self-management for chronic disease and enhance enablement of the consumer?

Scope of Question 3

The scope for Question 3 defined by ACI is as follows:

- Examples include, but are not limited to:
 - Self-management support, shared decision support tools
 - Health coaching, peer support
 - Tele monitoring
 - Telehealth
 - Patient reported outcome measures (PROMs) and patient reported experience measures (PREMs).
- ‘Monitoring mechanisms’ refers to mechanisms that track health behaviour, health outcomes
- Focus should be on the substance and on the elements that make the intervention or monitoring mechanism work, rather than on specific modalities or delivery method.
- For different types of interventions/monitoring mechanisms highlight, whenever possible, the populations and settings for which they are effective.
- As for Question 1, ACI is interested in health system and organisational factors and whether they support consumer enablement. If this information occurs in the selected studies, it should be flagged in a separate appendix.

Summary of the interventions

The search identified 25 reviews that investigated the effectiveness of a range of chronic disease self-management interventions. Detailed summaries of the reviews are presented in Attachment C: Evidence tables for Question 3

Table 15 in Attachment D. The reviews were a combination of low (n = 1), medium (n = 14) and high quality (n = 10). The lower scoring reviews were scoping or rapid reviews, whereas the highest scoring reviews were Cochrane systematic reviews.

For the purpose of presenting our findings, the reviews were categorised into five groups:

- multiple intervention types (n = 8),
- multi-component interventions that focused on tailoring interventions to person/group (n = 7),
- coaching interventions only (n = 2),
- interventions using information and communications technology only (ICT; n = 5)
- interventions with a focus on cognition (n = 2).

One of the objectives of this review was to identify the elements that make the intervention work or be effective. Six reviews did not attempt to explore these elements (Siantz ⁷⁶, Nolte ⁷⁷, Wildevuur ⁷⁸, Ehrlich ⁷⁹, Berzins ⁸⁰ & Williams ⁸¹). Three reviews attempted to do this, but were unsuccessful due to a lack of information reported in the source publication (Pare ⁸², Coster ⁸³ and Foster ⁸⁴). Fourteen reviews provided some discussion about the effective elements, but this was limited.⁸⁵⁻⁹⁸ The majority of reviews agreed that research was lacking in this area, and one referred to the mechanisms of action being a “black box” ⁸³. The reviews will be presented using the above groupings.

Multiple intervention types

Eight reviews were identified as having explored the effectiveness of multi-type and multi-component chronic disease self-management interventions in the general population.^{77, 81, 83, 92, 99-102} Overall, the interventions were found to improve a range of chronic disease self-management outcomes. However, most of the trials/studies were conducted with moderate to highly enabled participants, typically consisting of Caucasian adults, aged 45-60 years, educated and female. While there is a large body of evidence to support the use of multi-type and multi-component interventions amongst general patient populations, there is less evidence for their effectiveness amongst special needs and vulnerable groups. One review of medium quality, (Siantz) ⁷⁶, focused on interventions for patients with serious mental illness and chronic disease. Promising effects were identified especially in behavioural outcomes. However, none of the studies in this review presented results by racial or ethnic category, which may have an impact on intervention outcomes, as there is stigma associated with certain health conditions in different cultures. Overall, it is unclear how effective these interventions would be for younger, older or diverse people with higher levels of impairment.

Furthermore, the elements that make the interventions work are unclear as only two reviews, one of medium and one of high quality, were able to make comment on mechanisms. Quinones et al.⁹¹ reviewed self-management education interventions and found some evidence to suggest that intervention delivery mode could impact on intervention effectiveness. For example, group discussion and experiential learning were seen to be more effective than didactic education, although there was considerable variation in the interventions considered. Brady et al.⁹⁰ reviewed the Chronic Disease Self-Management Program and indicated that self-efficacy was the active component of the interventions. Three reviews did not report on the elements that made them work because it was not an aim (Berzins⁸⁰, Siantz⁷⁶, Nolte⁷⁷), whereas another two reviews were unsuccessful due to the lack of reporting in the individual studies (Coster⁸³, Foster⁸⁴).

Multi-component interventions that focused on tailoring interventions to person/group

Six reviews explored the effectiveness of interventions that involved some element of tailoring chronic disease self-management programs to either the individual patient^{95, 98} or minority groups.¹⁰³⁻¹⁰⁶ Radhakrishnan et al.⁹⁵ explored the effectiveness of customizing an intervention to an individual's specific needs, abilities and preferences. Their review found no impact on medication adherence, self-monitoring, exercise, smoking or diet control, however they were modestly successful in improving specific behaviours: dietary fat intake, levels of physical activity and screening. Coulter et al.⁹⁸ explored the effectiveness of personalised care planning and found that there were improvements in certain indicators of physical and psychological health status. However, the effects were not large, but did appear larger when the intervention was more comprehensive, intense and better integrated into routine care. The reviews were considered medium⁹⁵ and high⁹⁸ quality, and although tailoring interventions to the individual patient resulted in small positive effects, the cost and resource utilization associated with this type of intervention was highlighted as a major limitation.^{95, 98} Recommendations were made to reserve tailored interventions for those at greatest risk as there was stronger evidence to support tailoring for high risk patients.

Two of six reviews explored the effectiveness of interventions that were tailored to ethnic groups. Ehrlich et al.⁷⁹ explored whether self-management programs that were adapted or modified for ethnic minority or indigenous populations were still effective. The majority of studies were found to demonstrate a positive outcome following the intervention compared to standard care, but there was not enough evidence to suggest that it was better than the interventions without cultural adaptation. This was supported by Sidhu et al.⁹⁶, who reviewed lay-led, group-based, self-management interventions that were culturally and structurally adapted for minority ethnic populations. Interventions only led to short-term improvements in participants' self-efficacy, cognitive symptom management, self-rated health and frequency of exercise. There were small but statistically significant improvements in clinical measures in HbA1c, BMI, weight loss and systolic blood pressure: however, they were not maintained in the medium or long-term.⁹⁶ On the other hand, Foster et al.⁷⁷, who reviewed lay-led interventions, found similar short term effects, so it might be the lay-led component that is weakening the interventions, not the cultural adaptation. These findings suggest that there is still a gap in chronic disease self-management programs for culturally and linguistically diverse groups. Past research has attempted to adapt existing programs to other cultures, however this has had limited effectiveness and different approaches appear to be required.

The remaining two of six reviews explored specific types of interventions within specific groups, for example, a multicultural health worker (MHW) intervention for ethnic groups⁷⁷ and peer support interventions for people living in rural settings.⁹⁴ Goris et al.⁷⁷ explored the effectiveness of MHW interventions in chronic disease prevention and self-management in CALD populations. Several studies found significant improvements in participants' chronic disease self-management, and a meta-analysis of prevention outcomes indicated significant improvements (for example, uptake of breast screening, pap smears).⁷⁷ MHW interventions have the potential to improve chronic disease self-management outcomes because: they have shared demographic and cultural characteristics; they are able to develop trusting relationship with participants; they serve as a liaison or intermediary between health and social services; and they build individual and community capacity by increasing health knowledge and self-care through a range of activities.⁷⁷ The skill and knowledge of the MHW was a final element considered to be imperative to the intervention working. The authors recommended the development of universal protocols and training.

Lauckner et al.⁹⁴ explored community-based peer support initiatives for adults in rural settings living with chronic conditions. Peers were those who had shared experiences of the same chronic condition, those who shared the general experience of having a chronic condition, family/friends of those with the condition, or people with a shared risk of the condition based on shared social characteristics or culture. The intervention components primarily consisted of general social support and developing new skills. Once again positive

outcomes were evident across the studies. The elements that contributed to the intervention effectiveness were: promoting social connectedness (which motivated participants to complete or participate in program activities); reducing stigma; resonance (translating information in ways that make sense to them and/or match their particular culture); and empowerment.

Coaching interventions

Two reviews explored the effectiveness of coaching interventions, health coaching in general¹⁰⁷ and telephone coaching specifically.⁸⁵ Coaching was identified as an effective chronic disease self-management intervention^{84, 85}, particularly useful for vulnerable groups who have difficulty accessing services (telephone coaching).⁸⁵ Health coaching in general, has strong evidence to support positive effects in patients' weight management, increases in physical activity and self-efficacy, however specially-trained coaches were recommended.¹⁰⁷ In order for coaching to be effective it is important that the coaches are highly trained health coaches or psychologists, as they should have expertise enabling them to assess "the treatment of chronically ill patients, identify barriers to behaviour change, set health-related goals and make realistic plans for reaching these goals by listening, asking open questions, supporting and providing feedback".⁸⁴ Planned/scheduled and unscripted telephone coaching were also identified as important elements of the coaching intervention, especially for vulnerable groups. The planned/scheduled elements provided predictable, regular contact and support, while the unscripted element allowed the coaches to be responsive and reactive to the needs of the patient.⁸⁵ More research is required to understand how to encourage vulnerable groups to use coaching interventions. Some factors that were found to make telephone coaching an acceptable service for clients were: friendliness, helpfulness, convenient call scheduling and duration, knowledgeable staff, personally relevant call content and useful personally tailored advice.⁸⁵ However, services need to be cautious of burdening patients/participants with calls and appointments.

Interventions using information and communications technology only

Six reviews investigated the effectiveness of chronic disease self-management interventions with technology as a core component of the intervention.^{78, 108-112} The specific ICT applications included telemonitoring¹⁰⁹, mobile phone messaging⁸⁹, computer administered self-management programs¹⁰⁸, and person-centred IT⁷⁸ approaches. Pare et al. found that for home telemonitoring, the trend was towards patients achieving improved clinical outcomes, symptoms and perceived QoL. The authors attempted to explore the elements of the intervention, but found that it was not clear from the results whether improvement in the clinical condition of patients was the result of the use of the technology itself or other factors. Regardless, they stressed that home-tele-monitoring is a complementary intervention and not a solution that replaces primary care⁸². Jongh et al.⁸⁹ found limited evidence for mobile phone messaging, as there was no impact on clinical outcomes, some improvement in self-efficacy, and mixed findings for medication compliance and health service utilisation. Elements of SMS messaging that are likely to explain the intervention mechanism include the ability to provide quick and relevant information on the condition, providing a monitoring mechanism, and a channel for peer support. McDermott et al.⁸⁸ reviewed computer-based self-management programs, and found this approach did appear to be effective when compared to no intervention. They reported that complex behavioural change techniques incorporated into computer based programs were more likely to see larger improvements in outcomes than basic behaviour change techniques. Wildevuur et al.⁷⁸ reviewed person-centred IT interventions and found that there was some evidence to suggest a positive impact on clinical and behavioural outcomes. This was especially true in diabetes and CVD but rarely in stroke or cancer cases, with the most significant outcome being increased empowerment in self-care. Although the evidence for ICT interventions are promising, the application of these interventions is limited by the fact that they require additional resources such as mobile phones, computers, and telemonitoring equipment, and that the patient needs to be able to use them, therefore potentially excluding those with moderate or serious cognitive, visual or physical disability (Pare). The computer based interventions were problematic for older adults who had greater difficulty engaging in the program. It is also potentially problematic for those who require more human, face-to-face contact and can increase the risk of people becoming disengaged and isolated.⁸⁸ On the other hand, these types of interventions allow people to go at their own pace, and there is greater anonymity.⁸⁸

Cognitive-based interventions

Two reviews explored the effectiveness of interventions that focused on cognition, specifically using Acceptance and Commitment Therapy⁸⁷ and Problem Based Learning principles.⁸¹ Both reviews were of medium quality and the body of evidence behind using these is small and not yet well established. Graham et al.⁸⁷ found that for Acceptance and Commitment therapy, although there may be promise for specific

applications related to psychological flexibility and possibly treatment adherence, the poor quality of studies means findings are inconclusive. Williams et al.⁸¹ found that interventions did generate changes in chronic disease management among participants with diabetes, asthma, arthritis and coronary artery disease, while five of seven studies indicated that at least one outcome measure improved (knowledge, exercise, capacity to relieve pain, reduction in frequency of asthma symptoms, or increase in quality of life).

Table 10: Summary of intervention elements effective across different levels of enablement

	Individual factors	Health service factors	Social and physical environment factors
<p>Highly enabled</p> <p>Self-refer, highly aware of health state and initiate actions as they require</p>	<ul style="list-style-type: none"> Telephone coaching: Scripted is okay⁸⁵ Positive improvements observed due to interventions usually being developed and tested in these groups. 	<ul style="list-style-type: none"> Needs to be a formal protocol around the use of technical devices – quick response^{109 114 112 82, 111} Formalised training/protocol for health workers. 	
<p>Moderately enabled</p> <p>Require some prompting, reminding and assistance</p>	<ul style="list-style-type: none"> Telephone coaching: Scripted is okay⁸⁵ Positive improvements observed due to interventions usually developed and tested in these groups. 	<ul style="list-style-type: none"> Needs to be a formal protocol around the use of technical devices – quick response⁸² 	
<p>Major gaps/special needs</p> <p>Have particular barriers that make some aspects of caring for their health difficult at least currently</p>	<ul style="list-style-type: none"> Reactive and responsive telephone coaching is necessary⁸⁵ Telephone coaching was found to have the biggest improvement for this group⁸⁵ It is important to consider the feasibility of ICT interventions for special needs groups (e.g. moderate or serious cognitive, visual or physical disability, did not have a mobile phone)⁸² Computer based interventions may not be appropriate for those who require more human contact⁸⁸ Computer based interventions may be appropriate for those who want to go at their own pace (McDermott) Those with active disease and younger, with higher levels of impairment are more likely to discontinue their self-management courses.⁸⁰ 	<ul style="list-style-type: none"> Health services need to consider how to make this service acceptable for this group and encourage usage. Nature and content of programs should not overburden patients⁸⁵ Needs to be a proper protocol around the use of tech. devices – quick response⁸² HS need to consider the patients' ability to use computers and other tech. 	<ul style="list-style-type: none"> Telephone coaching provides greater access to services to a group with high needs who otherwise may be physically unable to gain access to services⁸⁵ Purely computer based programs may be problematic as they could lead to disengagement and attrition.⁸⁸

Supplementary searches to address identified gaps

After appraisal of the reviews identified above, we identified a number of gaps related to some of the main purposes stated for this evidence check. In particular, there was a lack of evidence in relation to interventions specifically for people with multiple conditions and for people with low levels of enablement. Additional searches of the grey literature were conducted to identify interventions and/or principles guiding service delivery for these groups.

Disease complexity – people with multiple chronic diseases

The grey literature presents specific interventions for people with multiple chronic diseases, and there was some discussion of principles that should underpin these interventions. The most common factors that underpin thinking about interventions for people with multiple comorbidities relate to characteristics of healthcare systems, healthcare provider support for patients, and characteristics of the communities in which people reside.

Several characteristics of healthcare systems featured in the literature. Structural issues included primary care services that are poorly connected with secondary care services, making it difficult for patients to engage in their care management, and care delivery providers that are often spread across different sections of the healthcare system and in different locations, which can lead to poor communication between members of a health team.^{113, 114} In light of this, improvement to information systems should be considered.¹¹⁵ Potential interventions can support increased access for people with complex conditions, and access options for services such as home-based palliative care.¹¹³ Of concern is that care delivery models are predominantly disease-specific and not designed to support people with multiple morbidities.¹¹⁶

Interventions in which healthcare services provide increased support for patients with multiple morbidities included helping patients to self-manage their health, to increase their functions in the community, and to make decisions about end of life care.¹¹³ Potential training interventions for healthcare providers could include awareness and understanding of the importance of providing care and support for people with chronic diseases and multiple morbidities.¹¹⁷

Community characteristics that may prove influential when considering intervention design include low social, environmental and socio-economic factors¹¹⁸, and taking into account difficulties in coping with physical and mental disorders, which is a particular issue for people living with multiple condition.^{113, 114} Deprived populations also experience higher levels of depression.¹¹⁶

Further recommendations in the literature were about: patient risk factors; how patients can be supported to manage their health; implementation, sustainability and allocation of resources for interventions; and recommendations for improvement to professional practice.

- There were recommendations that interventions should aim to reduce exposure to risk factors for multiple morbidities¹¹⁸, recognise the higher costs for people who are managing multiple morbidities¹¹⁶, and target the difficulties associated with self-management and the high risk of hospital admissions.¹¹³
- The literature indicates that changes to the way that patients are supported should be evidence-based, population-based and patient centred¹¹⁵, with adequate information to support implementation.¹¹⁹ Interventions in primary care practice, such as patient diabetes support groups led by a diabetes nurse educator with telephone follow up for patients with multiple chronic diseases, were recommended.¹¹⁵ The literature also recommends that improvement strategies are tailored for local communities.¹¹⁵
- Support by leaders¹¹⁷ and the involvement of healthcare professionals with specific expertise¹¹⁵ are reported as important factors for the effective and successful implementation and sustainability of interventions.
- There were three recommendations for improvements to healthcare professional practice: to support reflective healthcare practice¹¹⁷, to train registered nurse care coordinators in motivation interviewing¹²⁰, and to implement comprehensive case management by nurses for adults in the community who have long-term conditions.¹¹⁹
- In general, there was a claim that better allocation of resources could support interventions to improve the quality of care and access for patients, minimise waste and maximise appropriate use of those resources.^{113, 114}

Vulnerable groups – some cases of effective programs

The South East Healthy Communities Partnership (SEHCP) in Victoria specifically looked at the evidence to support interventions for CALD and migrant groups. Findings indicate that interventions targeting individual functioning, while recognising the need for culturally sensitive communication to reach vulnerable

populations, is essential. Community participative communication interventions are needed for implementation of successful strategies. Interventions involving the provision of culturally specific education — including promoting culturally sensitive communication practices — have been shown to be effective.⁷⁰ The National Health and Medical Research Council model of cultural competency development, an Australian model of cultural competency, appeared to be worthwhile for consideration by the SEHCP and its member agencies.⁷⁰ Print material is not recommended as the only medium for education interventions, specifically for vulnerable populations such as CALD, migrants or older adults.⁷⁰

Blignault et al.¹²¹ found that communication between health professionals and clients was not just a matter of hearing the words, but also understanding and incorporating cultural idioms. Two types of interventions were recommended for CALD populations: *intrapersonal interventions* that focus on how individuals from different cultural communities interact with the health care system, and *interpersonal interventions* that focus on cultural knowledge and practices.¹²¹

Migrant women are especially vulnerable in the Australian health system as they face challenges such as discrimination and low education, and are less likely to actively participate in prevention activities.¹²² Interventions that engage women in their own environments through interpreters help to overcome the barriers generated by discrimination and low education. Both verbal and nonverbal communication, feeling valued and understood, as well as having access to female clinicians and interpreters, were the main enablers for vulnerable women to participate in prevention and treatment services.¹²³

The Close the Gap intervention in the UK addresses the social and economic needs of vulnerable members with minimal government intervention. Effectiveness of some interventions among vulnerable populations has been demonstrated in some areas.¹²⁴

Telephone coaching interventions in vulnerable populations and people who have difficulty accessing health services has shown to be beneficial for some groups. Mechanisms include provision of health education information through both scripted and unscripted models of telephone coaching. A literature review reported improvements in health behaviour, self-efficacy, health status and satisfaction with the service for vulnerable populations through telephone health coaching models.⁸⁵ Telephone coaching was found to be helpful as a way of bridging the treatment gap for vulnerable patients (Aboriginal and Torres Strait Island people, those from culturally and linguistically diverse backgrounds, low socioeconomic status and those living in rural and remote areas) specifically for chronic conditions.¹²⁵ The main benefit as seen by patients was availability and affordability of health services through telephone health coaching.¹²⁵

The use of peer support programs has been shown to be effective in some vulnerable and CALD populations. Peer supporters (PSs) exercise autonomy and use their knowledge to deliver culturally tailored support, promoting meaningful relationships and producing better uptake of health services.¹²⁶ Through peer support programs vulnerable people become more confident, individually and collectively. The use of practical and educational support allows vulnerable groups to set goals they are capable of achieving. Success with small achievable changes increases confidence and motivation allowing people to self-manage and prioritise their own health.¹²⁶ Peer support programs, bringing together vulnerable people who are in similar situations and who share similar experiences and challenges, allow people to feel enabled and to set and achieve goals specifically targeted to them (rather than setting unachievable goals that may be appropriate for other groups of people who are not vulnerable). Peer support programs create a common bond between disadvantaged and vulnerable individuals while promoting social interaction and sharing of information and problems. This dialogue among similar individuals promotes a safe environment for participation. Concerns individuals may have about feeling out of place or being judged by the way they do or don't manage their health condition are considered to disappear as they become more confident.¹²⁶

Community participative communication interventions have been recommended as a valuable strategy for integrating individuals' perspectives into health education; these types of interventions lead to improved wellbeing and quality of life among vulnerable populations.⁷⁰

Question 4: What implications arise regarding the identification of the support needs and strategies to support individuals with varying degrees of complexity and enablement?

Scope of Question 4

- The ACI recognises that the population is heterogeneous in the level of enablement that can be achieved, as well as in the degree of complexity of the chronic conditions that need to be managed. Interventions and monitoring tools that are appropriate in one group of patients may not be appropriate in another. For example, highly enabled consumers with low complexity might benefit greatly from health apps, but health apps may bring no benefit to consumers with low levels of enablement. The focus should be on what types of tools and measurements work for what type of patient.
- From a conceptual point of view, the ACI would like to be able to identify, in the plane defined by level of enablement and degree of complexity, regions in which certain interventions and monitoring tools are effective. To illustrate this point, Figure 2 shows how two hypothetical findings would fit in this view: it is possible that health apps work well for highly enabled patients with low complexity, and that health coaching works well for highly enabled patients with moderate to high complexity.
- The ACI is particularly interested in the two dimensions of enablement and complexity, but there will be other dimensions that may be relevant to the framework. For example, evidence may point to a crucial role that age of the patient plays in overall patient engagement, or to the fact that certain types of interventions are only effective in certain age groups. These dimensions, which will emerge from the literature, should be reported on as well, since they contribute to the overall understanding of “what works for whom”.

Overview

The responses to Question 4 draw heavily on the responses to Questions 2 and 3. The question is essentially about being responsive to people in diverse situations with diverse levels of enablement. Such responsiveness has two core requirements:

1. The ability to assess and describe complexity and the enablement level/profile of a) individuals and b) specific target groups (for example, users of a particular service, older people with type 2 diabetes etc.)
2. The ability to make and enact decisions that effectively respond to people’s enablement status.

Based on this we consider the answers to this question in terms of a two-by-two matrix (Table 11).

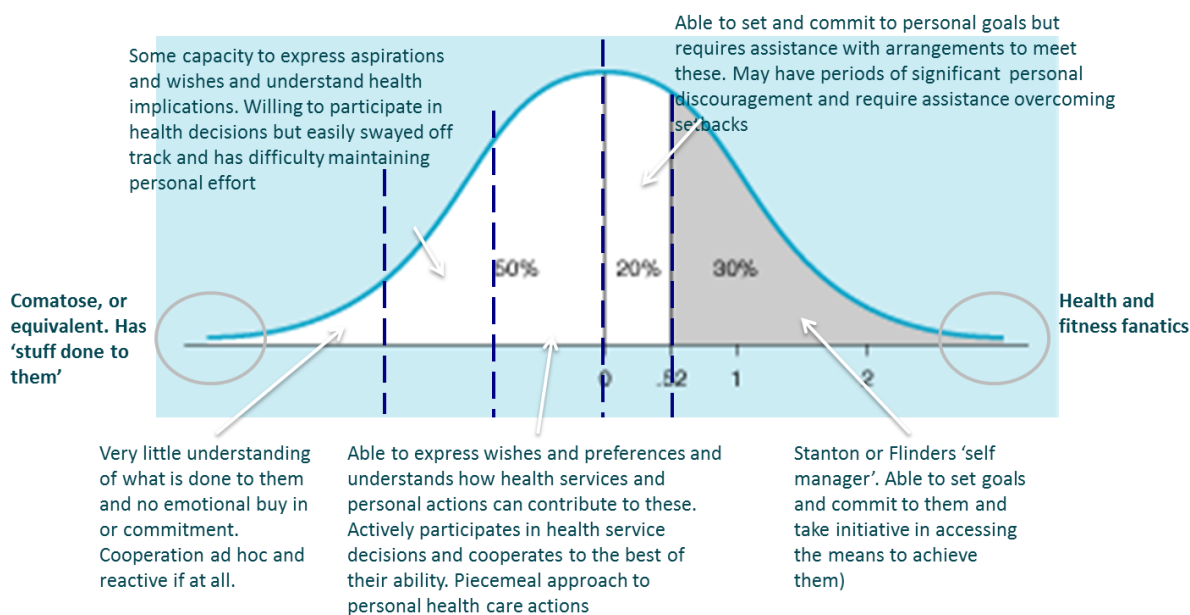
Table 11: Matrix of areas of response to levels of complexity and enablement

	Assessment and description of complexity and enablement	Planning and implementing responses
Individual	See Question 2 and, more qualitatively, the description of enablement features across levels in Table 3	See Question 3 and especially the grey literature in respect to developing strategies for people with low enablement
Group	See Question 2	See Question 3 including grey literature on interventions with specific groups

Understanding ‘levels’ of complexity and enablement

Often complexity of consumer needs is assessed in terms of basic and somewhat crude indicators such as the number of medical conditions. While this may have value with large groups, it has limited value in understanding the needs of smaller groups and of individuals. More sophisticated ways of analysing and describing complexity include:

- Applying a bio-psycho-social model
- Considering a dynamic, change-over-time perspective including life-course, disease stage, current crises, negative and positive cycles (NB this is captured well in the description of enablement and empowerment as ‘emergent statuses’ as described in Fumagalli et al.¹²⁷)
- Analysing specific enablement issues.



NB: The percentages are for purpose of illustration and will vary depending on the target group being considered.

Figure 7: Self-management it's not yes or no: descriptions of levels of self-management capability⁸

Assessing and understanding enablement of individuals

In the section on Question 2 we presented a framework and suggested tools for use in the assessment of enablement at the individual level (Table 9). In the analysis of tools, no tools were recommended for the type of use in which a score formed the sole basis for treatment and support decisions. Several tools were identified as useful assessment checklists to aid clinicians in assessing aspects of enablement as an adjunct to their decision-making, and one tool (PIH) was validated for use as a discussion and negotiation tool.

In addition, Table 3 presented a more qualitative, descriptive framework for analysing and describing peoples' levels in relation to four key components of enablement. Table 3 was developed based on an extensive set of case studies conducted with clients of a program for people at heightened risk of hospitalisation.⁸ In the same study a classification of levels of self-management capacity was developed, as shown in Figure 7. These levels are used later in this section to describe principles and general strategies that have been found to be useful at different levels of enablement (Table 12).

Assessing and understanding enablement of groups

Most of the analysis of tools discussed under Question 2 and presented in detail in Attachment B focused on the suitability of tools to distinguish between groups, to identify needs within groups and to assess change in groups over time or as a result of interventions.

Planning services for individuals: Interventions related to levels of enablement

Table 12 shows some overall descriptions of levels of enablement derived from the same set of case studies that were used to produce Table 3 and Figure 7. The table presents some of the common strategies that people found helpful at different levels in the case studies. These were largely confirmed in the evidence related to Question 3. Some additional strategies identified are shown in the final column of the table.

In general, as you move from higher to lower levels of enablement the strategies include:

- More attention to specific life circumstances including relationships, daily activities (time structuring), and physical and social environments
- More focus on relational components of enablement
- More emphasis on breaking information provision, goal setting, and action planning down into small, practically oriented chunks that are reviewed regularly
- More attention to identifying and addressing specific barriers
- More consideration of potential negative and/or virtuous cycles.

Table 12: Strategies for enablement for people with different levels of self-management capacity

Level of self-management capability	Strategies from original case studies	Additional strategies from this evidence check
(Classic ‘self-manager’) Largely independent in looking after health at least between acute health episodes. Some regular health improvement activities. Initiates engagement with health and related providers when necessary or when they consider it beneficial.	<ul style="list-style-type: none"> • Classic health education 	<ul style="list-style-type: none"> • On-line learning • Interactive technology • Providing up to date health information
(Supported ‘self-manager’) Able to set and commit to personal goals, but requires assistance with arrangements to meet these. May have periods of significant personal discouragement and require assistance to overcome setbacks.	<ul style="list-style-type: none"> • Health education • Coaching • Referral • Linkage to services • Some monitoring • Relapse planning 	<ul style="list-style-type: none"> • Periodic follow up
(Prompted ‘self-manager’) Able to express wishes and preferences, and understands how health services and personal actions can contribute to these. Actively participates in health service decisions and cooperates to the best of their ability. Piecemeal approach to personal health care actions.	<ul style="list-style-type: none"> • Coaching • Organise environmental stimuli • Assist to establish routines • Work with families 	<ul style="list-style-type: none"> • Provide periodic follow-up and prompt feedback • Encourage shared-decision making
(Reactive co-operator) Some capacity to express aspirations and wishes and understand health implications. Willing to participate in health decisions, but easily swayed off track and has difficulty maintaining personal effort.	<ul style="list-style-type: none"> • Assist to establish routines • Address crises • Address mental health conditions • Assist families 	<ul style="list-style-type: none"> • Provide periodic follow-up and prompt feedback • Promote social-connectedness • Respond and be flexible to needs • Tailor information to needs
(Non-co-operator) Very little understanding of what is done to them and no emotional buy-in or commitment. Cooperation is piecemeal and reactive if given at all.	<ul style="list-style-type: none"> • Find something they LOVE to do • Ensure crisis needs are met • Ensure that any mental health conditions are treated • Assist families or carers • Try to establish a relationship with one or two care providers 	<ul style="list-style-type: none"> • Address modifiable structural/physical barriers • Try to establish positive relationship with person/client (re-build trust)

Planning services for groups

Figure 8 presents a model for developing organisational responsiveness to the varied enablement levels, strengths and limitations of individuals, subgroups and communities.

This review has identified four main determinants of enablement that reach into separate and critical element of consumers’ lives. These include cognitive, affective/motivational, physical and relational components. To be person- and community-centred, these determinants need to be systematically considered and understood through needs assessments using tools such as the HLQ (A1). Needs assessment should not only be undertaken with clients entering services (A3), but also with those in the general community, as those with low enablement are often not able to gain access to and participate in services. Hence focusing only on the clients who manage to reach a service will be biased towards those with high enablement. Needs assessment tools such as the HLQ provide pertinent patient-experience information and/or service/practitioner quality information which can guide service improvements (A2).

When the full range of enablement needs of communities are defined and quantified, practitioners working in the region and local health services can more readily identify enablement interventions that respond to those needs (B1). This can be complex as the catchment of some services can be highly diverse in terms of the four enablement determinants, socio-demographics, cultures, languages and geographic distribution. It is of critical importance to formally ensure an adequate range of services, that is, services for clients with low enablement as well as those with high enablement.

Ideally, a health service has a carefully specified range of services (B1, based on empirical needs assessment) that match the service's catchment, and, importantly, practitioners have within their repertoire the skills to recognise and respond to the enablement needs of their clients (C1). The review clearly identifies that enablement interventions are not only related to one-on-one clinician-client interactions, but may include group, peer, telephone, ICT and other community engagement activities. Individuals and groups of individuals within communities require different enablement supports, depending on their current (and changing) needs, the complexity of their condition, and other client-, family- and community-level factors.

Organisations require access to a suite of appropriate assessment tools (B2). The use of client-level checklists to assess client enablement capability can support clinicians to take an optimal client-centred approach, and improve the patient-practitioner interaction. Several tools or components of tools (BBQ, HLQ, heiQ, HDS, ESPS, PHE) have the potential to support this. Such tools should be used judiciously: with short periods of application, the principles and broad concepts embodied in these tools can be incorporated into the daily repertoire of practitioners, but applied sporadically with novice practitioners. For many clients, engagement through a formal discussion tool (for example, PIH) can support mutual understanding and enable consensus on self-management goals.

Systematic collection of baseline, proximal outcome, and distal outcome data (A4) related to an organisation's plans and policies (C2) to promote enablement can drive improvement (B3). There are two groups of critical factors that determine success of quality monitoring:

1. Data collected from clients are absolutely meaningful to both the client and clinician (B2), are made available in a timely manner, and are used to create actionable messages that are acted upon (B1, C2).
2. Data collection and analysis process is not overly burdensome for patients, clinicians or services. This requires state-wide responsive web-based evaluation and reporting support.

When 1. and 2. work well, clinicians and managers not only welcome the data, but look forward to reports on the quality and impact of their endeavours with clients. Data are meaningful and build their knowledge of what works, for whom and why, over time. As noted above, collection of data from patients should be undertaken judiciously and targeted, building a body of knowledge and used to improve services (both the content of interventions and clinician skills). Outcomes assessment (A4) then feeds back into decisions about the effectiveness of the enablement strategies, assisting with making decisions about value for money, but balanced with strategic decisions about reducing health inequalities (C2). With clear organisational policy and programs focused on enablement, alongside evaluation and quality monitoring, gaps can be observed (C3) and these data can be used to inform training and purchasing decisions (B3).

Appendices

Attachment A: Evidence tables for Question 1

Table 13: Studies investigating associations between determinants, components and outcomes of consumer enablement

First Author and year	CD	Study characteristics	Determinants	Components	Outcomes	Conclusions about associations
Golub 2006	HIV/AIDS	Observational Cross-sectional	Relying on family and friends, problems with side effects	Feelings of aversion toward medications, conflicts with daily life activities	HIV medication adherence, deliberate alterations to the prescribed regimen	Four issues emerging in regards to non-adherence: 1) problems with side effects; 2) conflicts with daily life activities; 3) feelings of aversion toward the medications themselves; and 4) deliberate alterations to the prescribed regimen. Protective factors were relying on family and friends.
Gucciardi 2006	T2DB	Observational Cross-sectional	Ethnicity, English speaking, education, age	(implied – literacy)	Resource utilisation	T2DB patients who spoke English and were under the age of 60 were more likely to use and access resources compared to the patients who spoke Portuguese or Cantonese, were older than 60 years old or had low education.
Kripalani 2006	CHD	Experimental RCT Cross-sectional		Health literacy	Medication management capacity	Poor health literacy was associated with incomplete medication identification
Piette 2006	At least one of: diabetes mellitus, depression, heart problems, hypertension, or high cholesterol	Observational Cross-sectional	Ethnicity, income, education, gender, age, Medicaid coverage		Patient knowledge	Respondents were more likely to lack knowledge about their usual cost per prescription if they were non-white, had less education, were older, or had lower incomes. Non-whites, those with less education, those who were younger, and those with lower incomes were more likely to report not knowing about benefit caps.
Ashe 2007	Any CD	Observational Cross-sectional	Age, self-efficacy	Social support, mobility, psychosocial components, physical components (balance, strength, respiratory function, endurance)	Predictors of physical capacity and participation	Impairments/limitations increase the risk of inactivity more than the presence of the chronic disease itself. Self-efficacy was an important determinant and was significantly lower in the group who had the capacity but did not meet the recommended activity level.

Choi 2007	Depression	Observational Cross-sectional	Income, religiousness	Perceived loneliness, contact with friends, depending on others	Association between homebound/non home bound and depression	42% of the homebound group, compared to 13% of senior centre participants scored 5 or higher on the 15-item GDS. Perceived loneliness was an especially strong correlate of depressive symptoms in this group. A significantly higher proportion of the homebound group indicated that not having enough money to live on, being lonely or not having enough friends, and having to depend too much on other people were serious problems. A higher level of family support was significantly negatively associated with the GDS score, while a higher level of neighbour support was significantly positively associated with the GDS score.
Gauchet 2007	HIV	Observational Cross-sectional	Patient core values	Personal beliefs about medicine, confidence in physician	HIV medication adherence	Greater confidence in one's physician was related to greater adherence. Moreover, values and patients' beliefs about treatment also related to adherence. The effect of confidence in the physician was in part mediated by patients' beliefs about treatment.
Heisler 2007	Diabetes	Observational Cross-sectional	Ethnicity, age, gender, education, household income, HbA1c levels, coexisting depression, illness severity	Access to information from GP, participation in decision making, diet, feelings regarding self- efficacy, exercise, foot care	Importance of physician communication and participatory decision-making	Diabetes providers' provision of information and efforts to actively involve them in treatment decision-making were associated with better overall diabetes self-management.

Osborne 2007	Arthritis	Observational longitudinal	Sex, age, education, ethnicity, self-efficacy, medication use, general health, function, disability	Health services utilization, pain and fatigue self-efficacy, healthy behaviours, health distress	Efficacy of Arthritis Self-Management Course (ASMC)	ASMC leads to sustained improvement in health status. Participants experienced reduced levels of pain and fatigue, with decreased role limitations, and a reduction in health distress. Those who reported an increase in self-efficacy also reported less pain, fatigue, Health assessment questionnaire disability (HAQ) , health distress, and ADL role limitations at 6 months. Change in self-efficacy was unrelated to sex, age, years of education, or ethnicity.
Risser 2007	CHD	Experimental RCT longitudinal		Health literacy, self-efficacy	Medication adherence	The study is evaluating the reliability and validity of the SEAMS tool developed by the authors for assessment self-efficacy for medication adherence. Authors find SEAMS is 'reliable and valid'.
Chenoweth 2008	Parkinson's disease	Observational longitudinal	Age, gender, marital status, social support, self-efficacy, illness severity	sense of coherence, medicine knowledge, perceived health status	relationship between self-efficacy and self-management	Self-efficacy was the only characteristic that influenced self-management of the characteristics modelled. The model shows that patients who are married and have the support of their spouse or others have better self-efficacy and sense of coherence, and these two concepts are strongly connected. Sense of coherence is directly related to self-efficacy, coping and positive management.
Gallagher 2008	One or more of: chronic heart failure, chronic respiratory disease, Parkinson's disease and chronic schizophrenia	Observational longitudinal	Marital status, age, gender, health status, illness severity	orientation to life, sense of coherence, self-efficacy	self-management	Patients at risk of poor self-management included people with low self-efficacy, poor sense of coherence, older age and a primary diagnosis of chronic schizophrenia. As self-efficacy is the only predictor known to be amenable to intervention, self-efficacy enhancing support should be promoted.
Park 2008	CHF	Observational longitudinal	Age, sex, religious support, income, ethnicity, religiousness	provider information, positive and negative religious coping	Adherence with medical advice	Controlling for demographics, religious commitment was the sole predictor of adherence to CHF-related behaviours, an effect that remained when controlling for initial levels of adherence'. No demographic variable was a predictor of any of the three adherence factors.

Sato 2008	Rheumatoid arthritis	Observational Cross-sectional	Gender, education, marital status, economic status, age	Social difficulties, emotional support networks, level of self-care, pain.	Mental health	The patients reporting larger emotional support networks and those performing more self-care activities reported achieving higher levels of benefit-finding. Of all the factors examined, benefit-finding was the most significant predictor of mental health. This study found that social factors explained 9.5% of the variance in BF scores, and emotional support networks and self-care activities were shown to have independent positive effects on BF.
Ettner 2009	Diabetes	Observational Cross-sectional	Age, gender, income, education, ethnicity	Type of insurance, illness journey e.g. BMI, physical and mental health	Time spent on self-care	Extra time spent on self-care was greater for socioeconomically disadvantaged patients than for advantaged patients, perhaps because their perceived opportunity cost of time is lower or they cannot afford substitutes. Findings suggest that poorly controlled diabetes risk factors among disadvantaged populations may not be attributable to self-care practices.
Mann 2009	Diabetes	Observational Cross-sectional	Knowledge, self-efficacy, illness journey, regime complexity	Patient disease and medication beliefs	Medication adherence	Predictors of poor medication adherence were: believing you have diabetes only when your sugar is high, saying there was no need to take medicine when the glucose was normal, worrying about side-effects of diabetes medicines, lack of self-confidence in controlling diabetes, and feeling medicines are hard to take. Disease and medication beliefs inconsistent with a chronic disease model of diabetes were significant predictors of poor medication adherence.
Parchman 2009	type 2 Diabetes	Observational Cross-sectional	Age, sex, ethnicity	Community linkages, health service alignment to program, diet, exercise, glucose monitoring, medication adherence, self-reported health status	Control of CV risks	Only 25 (13%) of the 618 patients had good control of all three CV risk factors. Good control of these risk factors were positively associated with community linkages and delivery system design but was inversely associated with clinical information systems. The likelihood that all three risk factors were in good control increased as age increased, with female gender, and with maintenance stage of change for all four self-management behaviours.

Schnell-Hoen 2009	CHF	Observational Cross-sectional	Age, sex, ethnicity, marital status, living situation, education, family income, self-efficacy	Clinical factors: left ventricular function, and NYHA functional class, functional ability, comorbidity, self-management, self-care maintenance, psychological status	Self-care behaviours	Common self-care maintenance behaviours included taking medication as prescribed (95%), seeking physician guidance (80%), and following sodium dietary restrictions (70%). These behaviours were influenced by enabling characteristics such as psychological status (P = .030), ethnicity (P = .048), and comorbidity (P = .023). A unique finding was that self-care maintenance behaviours were significantly lower in aboriginal participants. The predisposing characteristic of self-efficacy influenced self-maintenance behaviours (P = .0002), overall self-care (P = .04) and number of hospital admissions (P = .0001).
Dossa 2010	Disability	Observational mixed-method: secondary longitudinal data, primary cross sectional data - qual and quant	Minority status, marital status, age, gender, self-efficacy, functional health status	Physician relationship, exercise, depression.	Program completion	Quantitative data showed that higher client baseline self-efficacy positively influenced completion and minority status negatively influenced completion. Qualitative data showed that higher focus on provider-client relationships was associated with high completion.
Allen 2011	End-stage renal disease (ESRD)	Participatory Action Research longitudinal	Age, sex, employment, cultural origin	Patient experience of clinical interactions, patient knowledge	Medication adherence	Three points of tension were identified: (a) between whole person care and "assembly line" treatment, (b) between patient knowledge and medical expertise, and (c) between shared decision-making and "digging to find out". Adversarial relationships are indicative of a lack of trust stemming from health professionals' failure to interact with patients as whole persons with unique expertise on their bodies, their experience of illness, and their lives.
Chiu 2011	Multiple Sclerosis	Observational Cross-sectional	age, gender, marital status, education, profession, ethnicity, self-efficacy	Illness journey, beliefs, risk perception, perceived barriers, intention, comorbidities, action and coping planning.	Prediction of physical activity	Recovery self-efficacy, action and coping planning, and perceived barriers directly contributed to the prediction of physical activity. Outcome expectancy significantly influenced intention and the relationship between intention and physical activity is mediated by action and coping planning. Action self-efficacy, maintenance self-efficacy, and recovery self-efficacy directly or indirectly affected physical activity. Severity of MS and action self-efficacy had an inverse relationship with perceived barriers and perceived barriers influenced physical activity.

Loeb 2011	Any CD	Observational Cross-sectional	Age, race, education, prior employment, marital status, self-efficacy, years of incarceration	Self-rated health status, mental state	relationships between self-efficacy for health management and health-promoting behaviours, health-monitoring behaviours, and self-rated health status	A significant positive relationship was found between self-efficacy for health management and the indexes measuring health-promoting behaviours, health-monitoring behaviours, and the single item rating for self-rated health. There was a tendency for education to be positively related to self-rated health, but not self-efficacy. Years of incarceration was not significantly related to self-rated health or self-efficacy. Being employed full-time prior to incarceration also was significantly related to higher levels of self-rated health.
Chubak 2012	Diabetes or CHF	Observational longitudinal	Age, gender, ability to afford meds, living situation, race, ethnicity	Satisfaction with care, health status, knowledge, skills, confidence, illness journey	Patterns and predictors of 1 year change in patient activation	Fifty-two percent of participants changed activation stage between baseline and follow-up. Of people who changed stage, 54% increased, and 46% decreased. Older age and worse baseline self-reported health were independent predictors of activation change. Changes in health status or serious adverse health events such as the occurrence of hospitalizations, new major diagnoses, or procedures were not related to changes in activation in this age group.
Joensen 2016	Type 1 Diabetes	Observational Cross-sectional	age, gender, education, occupation, hBa1c	social relations, diabetes duration, other chronic illness, quality of life, diabetes empowerment, diet, physical activity	Emotional burden	High emotional burden of diabetes was associated with being female, younger age, other chronic illness, low diabetes-specific support, low generic quality of life, low diabetes empowerment and high Hba1c. Low diabetes empowerment, low generic quality of life and low diabetes-specific support were associated with the largest difference in emotional burden.
Forbes 2016	Diabetes (1 and 2), CHD, and both.	Observational Cross-sectional	Income, age, gender, household size, employment status, ethnicity,	access to formal health care, duration of illness, comorbidity	Time spent on self-care	Higher income is associated with less time spent on self-care. Various measures of access to formal health care are found to not be associated with time spent on self-care. People from a lower socioeconomic position spend more time managing their condition even when there is universal entitlement to health care.

Wilski 2015	Multiple sclerosis	Observational Cross-sectional	Gender, age, place of residence, marital status, education, employment status, income	Social support, access to health services, illness journey, method of administering medication for MS	Self-management in MS	The final predictive model of self-management in MS was based on two main predictors: received support and available socioeconomic resources. Receiving adequate support from the closest relatives and having larger available socioeconomic resources are the strongest predictors of self-management in MS. A relationship between self-management in MS and gender as well as monthly income attributable to one family member was documented. Women with MS were involved in self-management to a significantly greater degree than men with this condition.
Chang 2015	Hypertension	Observational Cross-sectional	Age, sex, marital status, education, economic status, empowerment	Social support, depression, perceived severity of illness, self-care behaviour	Self-care	Empowerment was the strongest predictor of self-care, followed by social support, depression and perceived severity. The self-care scores of the men were higher than that of women. In particular, examination of self-care scores with respect to the level of education indicated that elderly individuals who had completed college education displayed higher scores than those who had only completed high school education.
Henselmans 2014	Any CD	Observational Cross-sectional	Age, sex, education, living situation, health literacy	Perceived efficacy with health care provider, perceived barriers with the healthcare provider, comorbidity, illness duration, information preference, level of activation		Most patients felt efficacious in consultations, although 46% reported barriers to participation and 39% had an interest in support. Patients most frequently endorsed relatively simple support. Patients perceived the least barriers and were least likely to endorse support when seeing a nurse. In multivariate models, consistent risk factors for low efficacy and perceived barriers were low health literacy and a low general patient activation. Female patients and patients with a lower educational level were more likely to report barriers than male patients or patients with an intermediate or a higher educational level.
Rich 2015	12 chronic diseases	Review – meta analysis Meta-analysis		Patient attitude, intention, behaviour	Medication adherence	While the theory of planned behaviour makes a useful contribution to our understanding of adherence in chronic illness, focusing solely on the theory of planned behaviour variables to predict and develop interventions to alter adherence may be insufficient. Its validity for predicting adherence behaviour in people with chronic illness is limited.

Sakar 2015	12 chronic diseases	Observational Cross-sectional	Age, ethnicity, gender, deprivation	comorbidities, number of medications	Systolic blood pressure (SBP)	The strongest predictor of mean SBP was the number of comorbidities. Other predictors included Afro-Caribbean ethnicity, β 0.05 ($p < 0.05$), South Asian ethnicity, β -0.03 ($p < 0.05$), age, β 0.05 ($p < 0.05$), male gender, β 0.05 ($p < 0.05$) and number of hypotensive drugs β 0.06 ($p < 0.05$).
Scott 2015	Coronary heart disease (19%); musculoskeletal (6%); pulmonary (3%); mental health (6%); endocrine (3%); and, multiple health conditions (63%)	Observational Cross-sectional	Environmental barriers, core values	Social and practical support, patient expectations, experiences, attitudes, psychological barriers, physical barriers	Physical activity maintenance	The findings suggest that congruence between prioritised outcome expectations and experiences of PA benefits determines whether one maintains or disengages with exercise. The level of congruence between core values (e.g., family), outcome expectations, and experiences appeared to influence successful or unsuccessful maintenance. The results in this study indicated that a reliance on social support can encourage a dependency that is detrimental for long-term PA.
Tanner 2014	Depression	Observational Cross-sectional	Age, gender, race, education, and living situation (alone/not alone) family support, type of health care received and frequency, history of chronic diseases, social isolation, number of medications	Loneliness, medication-taking practices, activities of daily living (ADLs); instrumental activities of daily living (IADLs), mental status, chronic diseases and conditions	Depressive symptoms	Family support was inversely associated with depression, indicating that individuals who reported family members to be less supportive were more likely to be depressed. Loneliness was strongly associated with depression. As loneliness increased, depression increased, yet, living status (living alone vs not living alone) was not significant. The association between functional status and depression was strongly positive, indicating that as dependence on others increased, depression increased. The relationship between loneliness and perceptions of family support is significant ($r = 0.33$, $p < 0.001$), as is the relationship between family support and depression ($r = 0.34$, $p < 0.001$).

Weaver 2014	Diabetes	Observational Cross-sectional	Economic, social, cultural resources, gender, education	Patient values, social relationships, living situation, knowledge	Health capability for dietary practices	Economic, social, and cultural resources conspired to undermine dietary management among most in the low resource group, whereas social influences significantly influenced diet among many in the medium group. High resource respondents appeared most motivated to maintain a healthy diet, and also had the social and cultural resources to enable them to do so.
Sigmund 2014	Diabetes	Observational Cross-sectional	Education, health literacy, health numeracy, disease/no disease		Patient ability to identify online test results	Both numeracy and health literacy were significant predictors of correctly identifying out-of-range values. Limited health literacy and numeracy skills are significant barriers to basic use of laboratory test result data as currently presented in some EHR portals. Regarding contacting their doctor, less numerate and literate participants with diabetes appear insensitive to the haemoglobin A1c level shown, whereas highly numerate and literate participants with diabetes appear very sensitive. Results suggest that many people find the task of identifying out-of-range values embedded in standard test result tables to be quite difficult.
Bidwell 2015	Heart failure	Observational Cross-sectional	Age, gender, marital status, education, employment, income, quality of life, Clinical HF characteristics (ejection fraction), New York Heart Association (NYHA) Class, duration of HF, hospitalizations, and medications	Caregiver perceived social support, relationship between patient and caregiver, cognition, and comorbid conditions	Patient and caregiver contributions to HF self-care maintenance and management	Significant individual and dyadic determinants of self-care maintenance and self-care management included gender, quality of life, comorbid burden, impaired ADLs, cognition, hospitalizations, HF duration, relationship type, relationship quality, and social support. Male patient gender was a significant determinant of worse patient self-care management. Non-spousal relationship type was a significant determinant of higher caregiver contributions to patient self-care management.

Jefferis 2014	12 chronic diseases	Experimental longitudinal	Age, gender, local social environment and leisure	Frequency of dog walking, use of public transport, comorbidity, depression, mobility limitations, exercise self-efficacy, exercise outcome expectations.	Adherence to physical activity guidelines	Those adhering to guidelines were younger, had fewer chronic health conditions, less depression, less severe mobility limitations, but higher exercise self-efficacy and exercise outcomes expectations. They rated their local environment more highly for social activities and leisure facilities, having somewhere nice to go for a walk and feeling safe after dark, They left the house on more days per week, were more likely to use active transport (cycle or walk) and to walk a dog regularly.
Rijken 2014	Any CD	Observational longitudinal	Gender, age, education, and household type	Self-rated health, illness duration,	Patient activation and association with self-rated health	Baseline self-rated health had a positive, indirect effect on patient activation at 18 months. In addition, the change in self-rated health over one year (from baseline) was a significant predictor of patients' activation scores. Patient activation is not a stable characteristic of people who have been chronically ill for years.
Schuler 2014	Rheumatism, asthma, orthopaedic conditions or inflammatory bowel disease	Observational longitudinal	N/A	N/A	Tool validation study	Reliability coefficients were high (0.80–0.94), and consistency coefficients (0.49–0.79) were always substantially higher than occasion specificity coefficients (0.14–0.38), indicating that the heiQ scales primarily capture person factors. The heiQ can be used to assess stable effects in important outcomes of self-management programs over time, e.g., changes in self-management skills or emotional well-being.
Schweier 2014	CHD or chronic back	Experimental longitudinal	Education, income, age, BMI		Physical activity and eating behaviour	Usage of the lebensstil-aendern website corresponds to more positive lifestyle changes. However, as-treated analyses do not allow for differentiating between causal effects and selection bias. Despite these limitations, the trial indicates that more than occasional website usage is necessary to reach dose-response efficacy. A lower educational level was related to lower rates of website usage.

Ryvicker 2012	18 chronic condition groups	Observational Cross-sectional	Ethnicity, age, gender, income, education, language	Obesity, patient activation, number of chronic conditions, number of activities of daily living/instrumental activities of daily living (ADLs/IADLs) for which the patient needed human assistance, indicators for specific chronic condition diagnoses	Hospitalization and emergency department (ED) visits	Activation was not a significant predictor of hospitalization or ED use in adjusted models. This non-finding raises questions about the PAM's ability to identify the highest-risk patients—and therefore, those in greatest need of enhanced self-management support—within a relatively high-risk, clinically complex population Non-Whites were more likely than Whites to have a hospitalization or ED visit. Patients with an income between \$25,000 and \$50,000 were more likely to have an ED visit than the lowest income group. Obesity was a strong predictor of both outcomes.
Chwastiak 2013	Cardiovascular risk factors	Observational Cross-sectional	Age, gender, race and ethnicity, marital status, and education	Obesity, level of training of staff, health status, health behaviour, mental health	Staff rates of preventative counselling	26.6% of the clinicians counselled more than half of their clients annually about all three cardiovascular (CVD) risk factors. Logistic regression showed that mental health providers who counselled clients about CVD risk factors were less likely to be obese, and were more likely to have received formal training about how to counsel clients about CVD risk.
Glasgow 2014	Diabetes	Experimental longitudinal	Age, gender, education, ethnicity, income, health literacy and numeracy, SBP, marital status	Physical activity, fat intake, computer usage, self-care activities, number of comorbid conditions	Program completion	Demographic factors (education, ethnicity, income) were associated with initial participation but not with later steps, and the converse was true of health behaviour variables. At later steps, health literacy and numeracy (for website engagement) and behavioural factors were the primary factors characterizing groups as more v. less successful. Baseline physical activity, baseline fat intake, greater baseline hours of computer usage, baseline diabetes self-care activities, and baseline systolic blood pressure were significant predictors of behaviour change at 4 months. Demographic factors were dominant in the earlier participation/nonparticipation steps of the program but did not differentiate groups after baseline assessment

Table 14: Limitations of studies related to Question 1

First Author and year	QATQS rating	Limitations
Golub 2006	N/A - Qualitative	The study doesn't focus on external factors except for relying on friends and family for reminders. Further research and attention is needed into the racial, ethnic, and gender differences in the experience of illness and treatment. Experience with health service missing.
Gucciardi 2006	Weak	Mixing forms of media within one category when literacy could be a major factor in determining use is a limitation of this study. Furthermore, data is based on patients' self-report rather than actual use of diabetes resources and patients may have exaggerated their use of resources to provide socially acceptable responses. Study participants were all Diabetes Education Centre users; thus, these findings may not be applicable to all individuals with diabetes, particularly those who do not use education services. Good focus on SES factors. Income is missing. Internal factors missing.
Kripalani 2006	Weak	It was conducted in a single institution, which serves a predominately low-literacy, African-American population with a large burden of chronic disease. The DRUGS measure could only be performed among patients who brought their medications to the clinic. While there were no important clinical differences between patients who brought and did not bring their medicines, it is possible that unmeasured factors (e.g., number of medications, actual understanding of the medication regimen, or adherence rates) were different among the subjects in this analysis. Reasons for exclusion included no mailing address or telephone number, unable to communicate in English, or had visual acuity worse than 20/60, significant psychiatric illnesses (physician diagnosis of schizophrenia, schizoaffective disorder, or bipolar disorder), overt delirium, or dementia. The study only looked at health literacy. Missing social, economic factors and gender.
Piette 2006	Weak	The analyses may underestimate the proportion of older adults with problems understanding their drug coverage, because respondents who reported that they did not have pharmacy benefits were excluded. Some of those respondents may have had drug benefits of which they were unaware. Respondents were classified as having a gap in their knowledge about co-payments and spending caps only if they explicitly reported that they did not know; other respondents who provided estimates may have reported erroneous information. Excluded: respondents who self-reported that they did not have pharmacy benefits, and older adults who are not online. Good consideration of SES factors. Consideration of internal factors missing and experience with the insurance provider.
Ashe 2007	Weak	Some of the questionnaires used in this study relied on self-report measurements and are therefore subject to recall and respondent bias. Study only captured the self-reported presence of a disease where the participant sought medical attention. Individuals were excluded if they were unable to communicate with the investigator over the phone and/or had an impairment or health concern that prevented the completion of testing. Individuals were excluded if they were unable to communicate with the investigator over the phone and/or had an impairment or health concern that prevented the completion of testing. Study focuses on internal factors. SES factors missing. Study does not report on social support measurement.
Choi 2007	Moderate	Sample size: study was 11.7% of the total meals on wheels population. Peers were 40% of the active pop of senior centres. Study focus on SES factors. Gender, ethnicity missing. Internal factors not a focus.

Gauchet 2007	Weak	Smallish sample size. Recruited patients during their quarterly consultation and required our participants to be healthy enough to attend a number of assessment appointments, our results may not generalise to those individuals with serious co morbid medical conditions such as cancer or hepatitis, or advanced AIDS. African women slightly underrepresented and White men and women slightly overrepresented. Good linkage of three categories of enabling factors. Buts other SES not considered e.g. income.
Heisler 2007	Weak	77.6% completed diabetes test kits. Black and Latino ethnicity, fewer years of formal education, lower annual household incomes, lack of insurance at the time of diagnosis of diabetes, longer duration of diabetes, current smoking status, more depressive symptoms, and lower evaluations of the quality of diabetes health care were each associated with not returning the HbA1c kit results.
Osborne 2007	Weak	Lack of a control group. Participants self-selected.
Risser 2007	Moderate	This study is evaluating a new self-efficacy tool SEAMS. It does not go so far to investigate system factors that support consumer enablement. The generalizability of results may also be limited by the predominance in our study of elderly, indigent, African American patients who take multiple medications, as well as the performance of the study at a single site.
Chenoweth 2008	Weak	Only those who could read and respond to questionnaires written or spoken in English eligible. Patients were excluded if they had been admitted more than once in prior 3 month period.
Gallagher 2008	Weak	Patients were considered ineligible for the study if they had been admitted to hospital for their study illness more than once in the previous 3 months, or if they could not read or write in English. All instruments depended on self-report so it can't be presumed that the relationships observed reflect self-management measured by other methods. Engagement with health service, income and ethnicity not included.
Park 2008	Weak	The sample consists almost entirely of men. Internal factors not included. Those who did not present to hospital or not using phones excluded. The assessment of adherence behaviours was based on self-report.
Sato 2008	Weak	The survey was partly developed by the authors. The participants in this study were likely to be highly educated than pop (not representative). Good focus on social economic environment. Income not considered. Health service factors not considered.
Ettner 2009	Weak	Not nationally representative. Participants self-reported. Only those who spoke English or Spanish. Focus on SES factors. Interaction with health service factors not considered.
Mann 2009	Weak	The study doesn't report on findings of SES factors. It focuses on the internal factors of knowledge and self-efficacy. It doesn't include health service factors. Participants self-reported. Cultural differences were not measured. Exclusion criteria included a new diagnosis of diabetes and terminal illness with life expectancy of <1 year.
Parch man 2009	Weak	The limitations of the study include the small number of primary care clinics from a limited geographic region of the country, limitations imposed by the cross-sectional nature of data, as well as selection bias of consecutive patients. Good consideration of three different factors. Income and education not considered though.
Schnell-Hoen 2009	Weak	Very small sample size. English speaking only. Self-report may have also led to over reporting of self-care behaviours. Unclear how they determined 'minority status' (either yes or no). Good consideration of SES and clinical. Health service factors missing.
Dossa 2010	Weak	Baseline client database only asked about minority or nonminority status, and therefore the study findings were restricted to these groups only. More than 15% missing data for English language, income, and education - could bias results. Cannot generalise this study to organizations other than community sites. Mainly women in both data sets. Good consideration of all three factors. Income and education missing.

Allen 2011	Weak	Small sample, cannot be generalised to all dialysis patients. Study limited to English-speaking patient-participants. Findings don't break down according to SES data. Focus is on patient descriptions of their experiences with health services. Internal factors not considered.
Chiu 2011	Weak	This study is testing a proposed model for physical activity self-management. Patients recruited by filling out link on website, and from 1 neurology clinic. All measures were self-reported.
Loeb 2011	Weak	English speaking only. Only Black or White selected. The mix of older prisoners could impact the mean self-ratings of health for an institution or group of institutions. Only two prisons. Truly random selection not possible. Exclusion criteria were life sentences or death sentences. Population in prison. Relationship with health service not included in study.
Chubak 2012	Weak	It was not possible to measure some potentially strong predictors of change in activation with the available data, such as changes in social support. Limited generalisability due to loss-to follow up. Many patients are white.
Joensen 2016	Moderate	Men, young people, and people with short diabetes duration, no complications, or poor glycaemic control are underrepresented in the full study population. A large proportion of the variance in emotional burden remained unexplained. The cross-sectional study design precludes inferring causal relationships. Other limitations include missing data for non-respondents on variables such as occupational status and educational level and limited measures of social relations. Good focus on SES but income not considered. Internal factors good. Health service not considered.
Forbes 2016	Weak	There is a relatively small sample size. Unclear whether the additional time spent on self-care is burdensome to the patient or whether it is beneficial to their health.
Wilski 2015	Weak	It is not clear whether the impact of support on self-management is direct or indirect. Social support may improve self-management through improved cognitive functioning, emotional condition, personal control, self-efficacy, confidence, self-esteem and other psychological variables. The data were obtained through self-report, which is subjected to bias and distortion. A risk that people who agreed to complete the questionnaire were not necessarily a fully representative sample of patients with MS. Inclusion criteria included: (1) diagnosis of MS; (2) no current alcohol/drug abuse; (3) lack of other comorbidities; and (4) absence of MS-related cognitive problems.
Chang 2015	Weak	Patients had to contact them from ads in newspapers – required a certain English speaking level and more likely 'medium' on enablement scale. More women than men. Ethnicity not considered nor health service factors.
Henselmans 2014	Weak	Sufficient Dutch required. The list of barriers presented to patients was based on a study among patients with cancer - may not have been comprehensive. Some patients commented they were not in contact with their care provider, which might make answering the questions difficult. Ethnicity not considered. But good consideration of three levels.
Rich 2015	N/A - Meta-analysis	Paper not focused on identifying determinants, but testing a theory.

Sakar 2015	Weak	There are limitations in the interpretation of QOF data as it was not designed as a research tool and therefore the data are not externally validated and inaccuracy in coding may also contribute to limitations of this data. Prevalence of hypertension in study pop is lower than estimates of national prevalence (in study pop 10.6%). Income, education, literacy, health service factors not considered.
Scott 2015	N/A - Qualitative	PA status is not measured at baseline in PARS. Attendance rates of > 75% of sessions was used to ensure activity levels were increased. The study was conducted within the UK healthcare system, which questions the effectiveness of these strategies across different cultural contexts. There was a low response rate from male unsuccessful maintainers and were under-represented in the study. Qual study focused on internal factors. Age, gender, ethnicity, education, income not included as determinants of investigation.
Tanner 2014	Weak	
Weaver 2014	N/A - Qualitative	Small sample size. Gender representative, minorities under represented, education levels in sample lower than Ontario average. Economic variation in sample far more limited than in society as a whole 'low to middle income working class' in sample. Ethnically homogenous study group.
Zikmund 2014	Weak	The study involved a hypothetic question e.g. presenting mock test results. The lack of personal relevance of these data may have inhibited participants' motivation to seek out and identify the out-of-range values. Recruited online. Not representative. Limited SES considered.
Bidwell 2015	Weak	Literacy and knowledge not considered nor ethnicity. This study enrolled caregivers who accompanied patients to appointments and did not pursue caregivers who were not present at the time the patient was enrolled.
Jefferis 2014	Weak	Those in a residential home excluded after completing, unclear why. Community dwelling only included. Low response rate from women. Neither health literacy, income, ethnicity not considered, nor health service factors examined.
Rijken 2014	Weak	Drawn from national panel but required to have sufficient mastery of Dutch and not mental illness. Low response rate on all 3 surveys. Self-reported health and patient activation were not assessed at the same measuring moments. Several determinants not assessed: ethnicity, income, non-English, and interactions with service providers.
Schuler 2014	Weak	Study is assessing usefulness of a tool rather than determinants per se. Some model assumptions could not be tested empirically.
Schweier 2014	Weak	Less than half of the intervention group visited the website. Used self-reported non-validated measures only, which are subject to response bias. Did not control for Internet literacy or Internet usage patterns. Dropout was higher among patients with coronary heart disease and in the intervention group. On average, those who dropped out were 1.9 years younger and had a €189 lower income. Inclusion criteria: Sufficient German language skills, and have no disabling cognitive deficits required.
Ryvicker 2012	Weak	Excluded: Chinese-speaking (n543), in care for more than 120 days at time of interview (n559), lived in smaller service regions (n 5 98), completed interview after discharge from homecare and not covered by insurance. Race only 'white or non-white'. Language only English or Spanish. Small sample size, low literacy could be an issue. Access to health service could have been included in determinants for investigation.
Chwastiak 2013	Weak	May not be representative of rural or larger urban community mental health centres. Rates of counselling were based on clinician self-report, rather than chart documentation or client report. The finding that obese clinicians are much less likely to counsel clients about CVD risk may have been biased, as obese clinicians were less likely to answer the question about counselling. Health behaviours were also based on self-report, and have a similar potential for over-estimation by respondents.

Glasgow 2014	Weak	The study was conducted in a single HMO and for a single Internet-based DSM program, and the SDM approach is exploratory in nature. 15.1% failed to complete baseline assessment. Latino ethnicity, education, and BMI were significant predictors of baseline assessment completion. 18.9% did not visit the intervention website at least monthly. Numeracy, baseline eating habits, health literacy, and baseline physical activity were significant predictors of website visits
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Note: QATQS – Quality Assessment Tool for Quantitative Studies by the Effective Public Health Practice Project. This standardised tool was developed to provide high quality systematic reviews to address the public health sector’s need for evidence to support practice. Overall methodological rating options were weak, moderate or strong, based on 8 sections (selection bias, study design, confounders, blinding, data collection methods, withdrawals and dropouts, intervention integrity, analysis).

Attachment B: Detailed analysis of tools for Question 2

Patient Activation Measure

Development and validation

Hibbard and colleague¹²⁸ sought to develop a measure of 'patient activation' within the US healthcare system. No specific *a priori* theoretical model used to drive initial development of the concept of activation. A review of published articles on skills and knowledge needed to successfully manage a chronic illness was conducted. Articles on self-care, self-management, doctor–patient communication, and using comparative information to inform health care choices were reviewed. Six domains were initially extracted. Consensus with experts was undertaken, then focus groups with patient to reword ideas into layman’s terms. An item pool was developed and subjected to Rasch analysis to generate four ordered (low activation to high activation) hypothetical stages: (1) believes active role is important, (2) confidence and knowledge to take action, (3) taking action, and (4) staying the course under stress. 75 items were developed to cover each of these domains.

The initial tool was subjected to a range of studies and was reduced to a 13 item scale, the PAM13 where respondents answer a four point, strongly disagree to strongly agree, scale. The PAM13 is now widely used and has been subjected to a limited number of validation studies.

The tool has been widely used (original tool cited 365 times) and has potential clinical application and has undergone adaptation, translation and validation in Canada¹²⁹, Germany^{17, 18}, Denmark²⁰ and the Netherlands²¹. Similarly, validation has been reported in a range of client groups and settings including mental health²², elective lumbar spine surgery²³, multi-morbid older adults²⁴ and in rural settings.²⁵

Validation studies are rarely done in settings without the original author, and until recently the license agreement prohibited independent testing the PAM. The PAM is a commercial product and licenses are available from Insignia Health Inc. (www.insigniahealth.com).

One of the only independent validation studies was recently undertaken in Canada where the authors concluded:

“In conclusion, our results suggest that PAM-13 provides a suitably reliable and valid instrument for research in patients with neurological conditions. However, our study suggests potential for measurement error and bias at low levels of activation. The implications of this error and bias may be of particular importance in clinical applications of the tool. Our study also suggests that measurement of activation may benefit from items and scaling tailored to specific diagnostic groups, recognizing their unique attributes and management challenges.”¹²⁹

The PAM has been widely adopted in the [English NHS](#) where a national license was purchased. No specific guidance was provided to Clinical Commissioning Groups and practitioners regarding its application however an [evaluation](#) of the application of the tool is underway and will be available in 2017.

In a 2013 review by the Hibbard and Greene¹³⁰, report that improvements in activation scores as a result of interventions have been small - on average between 2.5% to 6.5% and have associated with improvements in:

- Health-related quality of life
- Clinical indicators, such as low-density lipoprotein and blood pressure; adherence to treatment
- Improved health-related behaviour
- Increased participation in care
- Reduced symptoms, hospital readmissions, overnight hospital stays, and use of the emergency department.

Items of the PAM13

1. When all is said and done, I am the person who is responsible for managing my health condition.
2. Taking an active role in my own health care is the most important factor in determining my health and ability to function.
3. I am confident that I can take actions that will help prevent or minimise some symptoms or problems associated with my health condition.
4. I know what each of my prescribed medications do.
5. I am confident that I can tell when I need to go get medical care and when I can handle a health problem myself.
6. I am confident that I can tell a doctor concerns I have even when he or she does not ask.
7. I am confident that I can follow through on medical treatments I need to do at home.
8. I understand the nature and causes of my health condition(s).
9. I know the different medical treatment options available for my health condition.
10. I have been able to maintain the lifestyle changes for my health condition that I have make.
11. I know how to prevent further problems with my health condition.
12. I know how to prevent further problems when new situations or problems arise with my health condition.
13. I am confident that I can maintain lifestyle changes, like diet and exercise, even during times of stress.

Applicability in Australia

There are no known validation studies in Australia. The PAM has been used in one prominent Australian research study, the Queensland Living with Diabetes Study.^{131 132 133} These studies explored associations between the PAM and other measures such as quality of care and glycaemic control and found modest relationships.

	Related scales	Utility of scale
Physical capacity		
Cognitive capacity	<ul style="list-style-type: none">• (1) Believes active role is important	
Motivational capacity	<ul style="list-style-type: none">• (2) Confidence and knowledge to take action, (3) taking action, and (4) staying the course under stress.	<ul style="list-style-type: none">• A single scale that classifies respondents into four levels
Relational capacity		
Overall	<ul style="list-style-type: none">• Single hierarchical scale where a low score maps to some elements of Cognitive capacity and higher score maps to Motivational elements	<ul style="list-style-type: none">• Easily administered, 13 items, some uncertainty about utility of low score.

Recommendations

Given that there have been no specific validation studies in Australia, and that there is some uncertainty about the accuracy of the tool in people with low activation, it is recommended that local validation work be undertaken before wide application, and the outcomes of the UK evaluation are considered (2017).

The cost of a license is available upon request from www.insigniahealth.com study.^{131 132 133} These studies explored associations between the PAM and other measures such as quality of care and glycaemic control and found modest relationships.

Beliefs and Behaviour Questionnaire (BBQ)

Development and validation

The BBQ is 30 item questionnaire measuring beliefs, experiences and adherent behaviour on five-point Likert type scales. The tool does not explicitly state that it is measuring consumer enablement, however it is measuring related aspects, specifically pharmacologic and non-pharmacologic management and adherence. This can be considered a distal outcome.

The authors suggest it may be useful for identifying reasons behind intentional and unintentional nonadherence to both pharmacologic and non-pharmacologic management in patients with various chronic diseases¹³⁴ however several scales had unacceptably low reliability and the scale has not undergone further work and it has not been taken up in research or clinical settings so limited data exists to support its utility.

Applicability in Australia

Developed in Australia but has not received sufficient testing

	Related scales	Utility of scale
Physical capacity		
Cognitive capacity		
Motivational capacity	<ul style="list-style-type: none">• Confidence (patient's confidence in disease management)• Concerns (about their disease management).	<ul style="list-style-type: none">• Unclear
Relational capacity		
Overall		

Recommendations

Not recommended

Test of Functional Health Literacy in Adults (TOFHLA)

Development and validation

The Test of Functional Health Literacy in Adults (TOFHLA) was developed in the US in 1999 by an expert committee to measure “functional health literacy,” defined as assessing reading, writing, and numeracy skills, in relation to health care¹³⁵. Items were chosen from hospital texts by a literacy expert. A self-administered reading comprehension component includes three passages of texts and contains 50 items. It uses the modified Cloze procedure, where every fifth to seventh word in a passage is omitted, and the respondent selects a response from four options. An interviewer-administered numeracy component includes 17 items, where individuals are presented with cues and respond to questions based on hospital forms and prescription labels to test a patient’s capacity to comprehend and follow instructions around monitoring their condition (e.g., blood glucose), taking medication, keeping clinic appointments, and obtaining financial assistance.

Scores for the numeracy domain are transformed to a score out of 50 and added to the score from the reading comprehension domain (range: 0-100).

The raw score for the TOFHLA is converted to one of three categories: inadequate, marginal, or adequate health literacy. These categories were derived from an interpretation of the scores of 2,659 predominantly indigent and minority patients presenting for acute care at two urban hospitals in Atlanta and California, although the method is not explained.¹³⁶

A short version, S-TOFHLA, includes 36 reading comprehension and four numeracy items and are also converted to three categories.¹³⁵

Applicability in Australia

The TOFHLA requires participants to be able to read and write and was designed to be administered within 22 minutes however it has been observed to take 20 to 40 minutes in clinical settings in Australia.¹³⁷ It has substantial ceiling effects (that is, many respondents score the maximum score (>60%) and for people with low literacy levels, they have found the completion of written tests stigmatising.¹³⁷ An Australian version of the TOFHLA is available.¹³⁸

	Related scales	Utility of scale
Physical capacity		
Cognitive capacity	<ul style="list-style-type: none">• Health-related reading skills• Health-related numeracy skills	
Motivational capacity		
Relational capacity		
Overall	<ul style="list-style-type: none">• Limited breadth	<ul style="list-style-type: none">• Acceptable psychometric properties but low practicality in clinical settings

Recommendations

The TOFHLA is a robust measure of functional health literacy which is a component of enablement. It is freely available but is not practical in clinical settings due to being interviewer administered and the length of time it takes to complete. It has not been tested for sensitivity to change or for monitoring.

Health Literacy Questionnaire (HLQ)

Development and validation

The HLQ is a licensed tool owned by Deakin and Monash Universities. It currently incurs a nominal license fee of \$250 per project payable to Deakin University. The licensing is in transition where the intention is to make the license free of charge to not for profit organisations by the end of 2016.

The HLQ was developed in Australia and is a multidimensional health literacy measure with nine independent questionnaires with 4-6 items. It has been rigorously validated in a wide range of healthcare and community settings. It was designed for, and being used for, surveys, evaluation, service improvement, quality monitoring and quality improvement. Across the dimensions, it is both a measure of elements of an individual's ability to understand, find and engage with health information and health services, and a measure of their lived experience of engaging with services and practitioners.¹³⁹

It was developed using a 'validity-driven' instrument development approach. Grounded consultations (workshops and interviews) were used to identify broad conceptually distinct domains. Item development from consultations following a strict process. Psychometric analyses included both classical test theory and item response theory. Cognitive interviews were used to test questions. Items and scales were initially tested in a calibration sample of 634 people from community health, home care and hospital settings. A replication sample of 405 people who were recently discharged from an emergency department (Barwon Health).

A follow-up study was undertaken to explore the psychometric properties of the HLQ with respondents from a diverse range of community-based-organisations with the principal goal of contributing to the development of a soundly validated evidence base for its use in community health settings¹⁴⁰. Most analyses were conducted using Bayesian structural equation modelling that enables rigorous analysis of data but with some relaxation of the restrictive requirements for zero cross-loadings and residual correlations of 'classical' confirmatory factor analysis. Scale homogeneity was investigated with one-factor models that allowed for the presence of small item residual correlations while discriminant validity was studied using the inter-factor correlations and factor loadings from a full 9-factor model with similar allowance for small residual correlations and cross-loadings. Measurement invariance was investigated scale by scale using a model that required strict invariance of item factor loadings, thresholds, residual variances and co-variances. The HLQ is highly reliable, even with only 4 to 6 items per scale. It provides unbiased mean estimates of group differences across key demographic indicators. While measuring relatively narrow constructs, the 9 dimensions are clearly separate and therefore provide fine-grained data on the multidimensional area of health literacy. These analyses provide researchers, program managers and policymakers with a range of robust evidence by which they can make judgements about the appropriate use of the HLQ for their community-based setting.¹⁴⁰

Two HLQ scales have been used in the Danish National Health Survey.¹⁴¹ Recently the New Zealand Government purchased a license for its inclusion in the New Zealand National Health Survey (Personal communication; Chloe Lynch, Senior Advisor, Health Survey, Health and Disability Intelligence Unit, Client Insights and Analytics, NZ Ministry of Health).

A large study among Danish people with diabetes (N=1399) as shown that higher HLQ levels are associated with better glycaemic control – 8 of the 9 HLQ were associated with HbA1c levels. This study provided new insights into potential targets for future diabetes self-management support interventions and into how practitioners and organisations can respond to the health literacy needs of people with diabetes (Kasper Olsen, Steno Diabetes Centre, Denmark, submitted for publication).

Intensive psychometric studies have been undertaken in diverse community settings in Denmark¹⁴², including the Danish national health survey¹⁴¹, in Slovak Republic¹⁴³ with further studies underway in Germany, Netherlands, France and Canada.

Applicability in Australia

The HLQ was developed in Australia, cited 43 times since 2014, and several validation studies have been undertaken.

In an attempt to obtain data on the interpretation of the HLQ from both the patient and clinician perspective in-depth qualitative interviews were undertaken in the Barwon Health Hospital Admission Risk

Program (HARP) setting. Sixteen patients with complex needs (that is, low and very low enablement) completed the HLQ and were interviewed to explore the reasons for their answers. Also, the clinicians of each of these patients completed the HLQ about their patient, and were interviewed to discuss the reasons for their answers. Thematic analysis of HLQ scores and interview data determined the extent of concordance between patient and clinician HLQ responses, and the reasons for discordance. Concordance was found to be high, however where non-concordance was observed, useful insights that demonstrate the reasons for patient-clinician differing views were exposed. This study shows that the HLQ can act as an adjunct to clinical practice to help clinicians understand a patient's health literacy challenges and strengths early in a clinical encounter. Importantly, clinicians can use the HLQ to detect differences between their own perspectives about a patient's health literacy and the patient's perspective, and to initiate discussion to explore this.¹⁴⁴

The HLQ has been used as an evaluation tool within an Ophelia (OPTimising HEalth LIteracy and Access) intervention by the Royal District Nursing Service.¹⁴⁵ The HLQ supported a structured method for the healthcare services to co-design interventions to respond to the health literacy needs of their clients.

Psychometric questionnaires are often difficult to interpret as a result of benchmarks or clinically significant cut points. The HLQ was recently administered to a population-based sample of adults in the South East Melbourne Primary Care Network (n=1500). These other data are currently being collated to support development of percentile norms to assist program managers and researchers to easily understand each of the scales benchmarked against national norms.

	Related scales	Utility of scale
Physical capacity		
Cognitive capacity	2. Having sufficient information to manage my health 5. Appraisal of health information 7. Navigating the healthcare system 8. Ability to find good health information 9. Understanding health information well enough to know what to do	<ul style="list-style-type: none"> Each scale has minimum items (4-6) and are highly reliable
Motivational capacity	3. Actively managing my health	<ul style="list-style-type: none"> Scale has minimum items (4) and is highly reliable
Relational capacity	1. Feeling understood and supported by healthcare providers 4. Social support for health 6. Ability to actively engage with healthcare providers	<ul style="list-style-type: none"> Each scale has minimum items (4-5) and are highly reliable
Overall	Substantial breadth	<ul style="list-style-type: none"> One or more scales are useful to measure elements of enablement

Recommendations

The HLQ scales provide substantial coverage of the enablement concept. Specific scales can be selected to inform quality and monitoring initiatives.

Health Education Impact Questionnaire (heiQ)

Development and validation

The heiQ is a licensed tool that incurs a license fee based on the number of administrations. While this is an exclusion criterion, a brief summary of its properties is provided.

The heiQ is a self-report patient outcomes measure that was developed 10 years ago in Victoria to be a user-friendly, relevant, and psychometrically sound instrument for the comprehensive evaluation and quality monitoring of patient education programs and related activities.¹⁴⁶ It has been cited 145 times since 2007. The present version (Version 3) measures 8 constructs by multi-item composite scales:

1. Health Directed Activities (HDA),
2. Positive and Active Engagement in Life (PAEL),
3. Emotional Distress (ED),
4. Self-monitoring and Insight (SMI),
5. Constructive Attitudes and Approaches (CAA),
6. Skill and Technique Acquisition (STA),
7. Social Integration and Support (SIS) and
8. Health Services Navigation (HSN).

The heiQ was developed following a grounded approach that included the generation of a program logic model for health education interventions and concept mapping workshops to identify relevant constructs.¹⁴⁶ Based on the results of the workshops, candidate items were written and tested on a large construction sample drawn from potential participants of patient education programs and persons who had recently completed a program. The number of items was reduced to a 42-item questionnaire measuring 8 constructs and again tested on a replication sample drawn from a broader population of attendees at a general hospital outpatient clinic and community-based self-management programs. Confirmatory factor analysis (CFA) supported by IRT analysis was used for item selection and scale refinement. In subsequent revisions leading to Version 3, the number of Likert-type response options was reduced from 6 to 4 on advice from users (they are now strongly disagree, disagree, agree, strongly agree with slightly options removed) and the number of items was reduced to 40.

The general eight-factor structure of the original version of the heiQ was replicated by Nolte¹⁴⁷ who investigated its factorial invariance¹⁴⁸ across a traditional baseline to follow-up (pre-test, post-test) design as well as across a post-test compared with a retrospective pre-test ('then-test') design. Nolte's results supported the stability of the factor structure across measurement occasions and questionnaire formats (configural invariance) and the equivalence of item factor loadings (metric invariance) and intercepts/thresholds (scalar invariance) of the heiQ when used in the traditional pre-post design. More recently, the factor structure and factorial invariance of the 40 items that constitute Version 3 of the heiQ was investigated using a large sample of 3,221 archived responses.¹⁴⁹ The original eight-factor structure was again replicated and all but one of the scales (4. SMI) was found to consist of unifactorial items with reliability of ≥ 0.8 and satisfactory discriminant validity. Nolte's findings of satisfactory configural, metric and scalar invariance were replicated across baseline to follow-up for all scales, and strict measurement invariance was also strongly supported across important population sub-groups (sex, age, education, ethnic background). Further, it has also recently been demonstrated that change scores on the heiQ scales are relatively free from social desirability bias.¹⁵⁰

These findings support the high level of interest in the heiQ in the evaluation of health education and self-management programs, particularly for use as a baseline to follow-up measure in experimental studies, other evaluation designs and system-level monitoring and evaluation. In particular, they give users confidence that all heiQ scales are providing relatively unbiased and equivalent measures across baseline to follow-up data. Norms and benchmarks have also been developed to support the practical but appropriate interpretation of both individual and group data from the application of the heiQ in community and health service settings in Australia.¹⁵¹

The heiQ scales are all independent questionnaires and may be used separately when specific impact elements are being analysed. It has been found to be a sensitive measure of change and provides a profile that directly informs quality improvement activities in the chronic disease self-management sector. It is used as part of a national quality approach in England through *Self Management UK* [see report](#).¹⁵²

The heiQ has undergone extensive psychometric testing in several countries and has been consistently found to be robust across Western cultures such as Germany, France, Denmark, and Canada. Evaluations have shown that it is robust for comparing across chronic conditions (France ¹⁵³, Germany ^{154 155, 156}, and has been demonstrated to be a robust measure of empowerment in cancer (Canada ¹⁵⁷).

Applicability in Australia

Except where stated, the above studies have been undertaken in Australia. The heiQ is available in many of the common languages of migrants living in Australia.

	Related scales	Utility of scale
Physical capacity		
Cognitive capacity	4. Self-monitoring and Insight 6. Skill and Technique Acquisition	<ul style="list-style-type: none"> Each scale has minimal items (5) and are highly reliable
Motivational capacity	1. Health Directed Activities 2. Positive and Active Engagement in Life 3. Emotional Distress 5. Constructive Attitudes and Approaches	<ul style="list-style-type: none"> Each scale has minimal items (4 - 6) and are highly reliable
Relational capacity	7. Social Integration and Support 8. Health Services Navigation	<ul style="list-style-type: none"> Each scale has minimal items (5) and are highly reliable
Overall	Substantial breadth	<ul style="list-style-type: none"> One or more scales are useful to measure elements of enablement

Recommendations

The heiQ was designed specifically to measure outcomes of chronic disease programs and to support quality improvement. Each scale appears to measure some element of enablement. Each scale has been validated and can be used as an independent questionnaire to cover specific elements of enablement.

Chronic Disease Self-Efficacy Scales (CDSSES)

Development and validation

The concept measured within self-efficacy scales is based on Bandura's social cognitive theory¹⁵⁸ Miles et al.¹⁵⁹ summarise self-efficacy as "a concept describing a set of beliefs about oneself, specifically about one's ability to perform certain behaviours within a particular environment. Self-efficacy is not only related to specific behaviours but also to the beliefs that people have about how they can cope in adverse situations".

A wide range of questionnaires have been developed to measure self-efficacy in people with chronic conditions however most have been found to have psychometric limitations.¹⁶⁰ A review by Miles et. al.¹⁵⁹ found 13 scales and undertook an evaluation of five with sufficient publications on their measurement properties; the Arthritis Self-Efficacy Scale, the Chronic Disease Self-Efficacy Scale, the Pain Self-Efficacy Questionnaire, the Chronic Pain Self-Efficacy Scale, and the Self-Efficacy Scale. Each had some gaps, although all had reasonable reliability. The most widely used in the chronic disease self-management sector are scales developed at Stanford University and applied in the Stanford Chronic Disease Self-management program¹⁶¹. This tool was based on an earlier longer version for people with arthritis¹⁶², however no further specific studies that explore its psychometric properties or utility were identified.

Self-efficacy remains a popular process measure in the health sector. There is a plethora of disease-specific and context-specific scales available with 15 to 20 new publications per year providing evidence related to these conditions or contexts. This intensity of research reflects a move away from a focus on 'general self-efficacy', which is probably difficult for people (especially people with low enablement) to conceptualise, to more tangible and specific actions or behaviours in one's daily life.

Applicability in Australia

The CDSSES scale was used in a controlled trial of a new self-management program developed by Arthritis NSW and evaluated by the University of NSW.¹⁶³ Self-efficacy improved similarly in the intervention and control groups. The CDSSES was also applied in a large national convenience sample of attendees of the Arthritis Self-management course.²³

	Related scales	Utility of scale
Physical capacity		
Cognitive capacity		
Motivational capacity	<ul style="list-style-type: none">• Self-efficacy	<ul style="list-style-type: none">• Various, brief scales
Relational capacity		
Overall	<ul style="list-style-type: none">• One element of enablement	<ul style="list-style-type: none">• Single score provided

Recommendations

Systematic measurement of general self-efficacy is unlikely to provide instructive data that will provide insights into enablement drive quality improvement and improve outcomes.

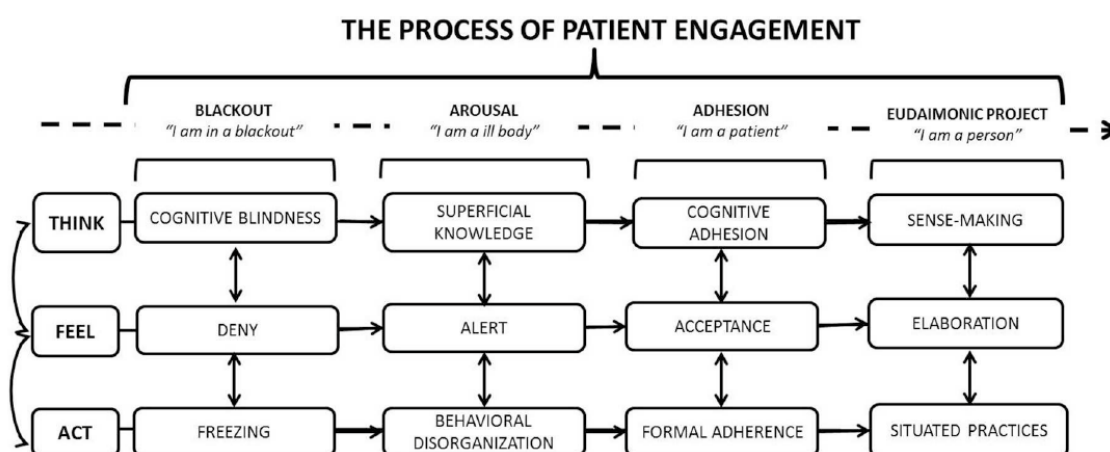
Patient Health Engagement Scale (PHE)

Development and validation

The PHE is a new scale first published in 2015. Graffigna et al.¹⁶⁴ claim that the concept of engagement offers a more holistic consideration of the psychological elaboration of the patient about his/her health condition and presents a multi-stage development.¹⁶⁵ Precisely, patient engagement is a “process-like and multi- dimensional experience, resulting from the conjoint cognitive (think), emotional (feel), and conative (act) enactment of individuals toward their health management”. In this process, patients go through 4 subsequent positions (blackout, arousal, adhesion, and eudaimonic project; see **Error! Reference source not found.**).

The PHE is a valuable contribution to the concept of enablement given its careful inclusion of individuals who are profoundly not engaged. The questionnaire has nine items that generate a single score. The scale was developed using the above *a priori* theoretical model and application of classical and Rasch psychometric techniques. Nine items were applied in a small pilot (n=48) and five items were then validated in a larger sample of people with chronic conditions (n=382).^{164, 166}

Figure 9: The patient health engagement model



Applicability in Australia

The questionnaire was developed in Italy and no published studies are available beyond the initial validation. The tool appears to be freely available.

	Related scales	Utility of scale
Physical capacity	<ul style="list-style-type: none"> Unclear 	
Cognitive capacity	<ul style="list-style-type: none"> Unclear 	
Motivational capacity	<ul style="list-style-type: none"> Unclear 	
Relational capacity		
Overall		<ul style="list-style-type: none"> Many items are somewhat complex Measures an extremely wide breadth of engagement

Recommendations

The PHE has promising concepts but insufficient validation and utility data are currently available.

Health Distress Scale (HDS)

Development and validation

The HDS is part of the Stanford University [recommended set of questionnaires](#) for evaluating chronic disease self-management programs.¹⁶¹ It is a modified version of the MOS health distress scale¹⁶⁷ where 4 of the original 6 items are used. It is a simple scale with high reliability. No further specific studies that explore its psychometric properties or utility were identified.

Items include:

1. Were you discouraged by your health problems?
2. Were you fearful about your future health?
3. Was your health a worry in your life?
4. Were you frustrated by your health problems?

Applicability in Australia

The HDS was used in a controlled trial of a new self-management program developed by Arthritis NSW and evaluated by the University of NSW.¹⁶³ Health distress improved similarly in the intervention and control groups.

	Related scales	Utility of scale
Physical capacity		
Cognitive capacity	<ul style="list-style-type: none">• Health distress	
Motivational capacity	<ul style="list-style-type: none">• Health distress	
Relational capacity		
Overall		<ul style="list-style-type: none">• Short narrow scale that probably picks up low levels of enablement.

Recommendations

Health distress is a component of enablement. The scale provides limited information on enablement but has had limited use.

University of Rhode Island Change Assessment Questionnaire (URICA)

Development and validation

The University of Rhode Island Change Assessment (URICA)¹⁶⁸ is one of the most commonly used measures of motivation to change – an important component of enablement.

The URICA captures data on four of the five theoretical stages of change: precontemplation, contemplation, action, and maintenance. It includes eight questions for each of the four stages, i.e., a total of 32 items. The measure can be scored to provide a continuous measure of readiness to change, often referred to as a composite score, or to provide stage profiles. The URICA has undergone several psychometric evaluations indicating it has, generally, acceptable theoretical consistency, concurrent, and discriminant validity^{169 170}. Many studies of its factor structure suggest some inconsistencies and it has generally not been found to have adequate predictive validity.^{171 172 173}

The four theoretically-derived subscales are, precontemplation (e.g. "I am not the problem one, it doesn't make sense for me to be here"), contemplation (e.g. "I have a problem and I really think I should work on it"), action (e.g. "I am finally doing some work on my problem"), and maintenance (e.g. "It worries me that I might slip back on a problem I already have, so I am here to seek help").

Applicability in Australia

The URICA has been used in Australia mainly in the rehabilitation and mental health sector, including in addiction and in eating disorders. Laplante-Lévesque et al. 2013 examined the URICA in the audiology setting and identified a different factor structure compared with the original however other properties were acceptable.¹⁷⁴ The tool appears to be mainly used to explore the stages of change theory, and to inform application and adherence to some psychological interventions.

	Related scales	Utility of scale
Physical capacity		
Cognitive capacity	<ul style="list-style-type: none">• Precontemplation, contemplation	<ul style="list-style-type: none">• May inform psychological interventions
Motivational capacity	<ul style="list-style-type: none">• Precontemplation, contemplation, action, maintenance	<ul style="list-style-type: none">• May inform psychological interventions• May explain success of some treatments
Relational capacity		
Overall		<ul style="list-style-type: none">• Limited

Recommendations

While stages of change remain a popular and measurable concept, it may not have sufficient utility to inform enablement strategies or improve quality and impact of interventions. Not recommended.

Rapid Estimate of Adult Literacy in Medicine (REALM)

Development and validation

The Rapid Estimate of Adult Literacy in Medicine (REALM) was developed in the United States to assist physicians to identify adults with limited reading skills in the primary care setting.¹⁷⁵ It was modelled on the Wide Range Achievement Test (WRAT), a standardised literacy test that assesses the pronunciation of a list of words that the respondent reads aloud.¹⁷⁵ The 125 words, chosen from materials used in primary care, are arranged in three columns according to the number of syllables in ascending order of difficulty. A point is allocated for each correctly pronounced word. A shortened version, the REALM-S, comprising 66 items, was developed to reduce administration time and enhance uptake within the clinical setting.¹⁷⁶ It takes 1 to 2 minutes to complete. The raw score for the REALM-S (0 to 66) is converted to a US school grade estimate of reading ability.

The REALM focuses on functional health literacy and has been criticised for weak psychometric properties^{177 178} including not being sensitive to change over time and that it is potentially humiliating to complete for those with low health literacy or low enablement. Importantly, while respondents may be able to recognise and pronounce a word, the test does not distinguish between those who do and do not understand what the words mean.¹⁷⁹

Applicability in Australia

The REALM has had limited application in Australia¹³⁸ and appears to have limited utility.^{178 138}

	Related scales	Utility of scale
Physical capacity		
Cognitive capacity	<ul style="list-style-type: none">• Functional health literacy (reading ability)	<ul style="list-style-type: none">• Easy to administer (per interview), may cause embarrassment for those who cannot read.
Motivational capacity		
Relational capacity		
Overall		<ul style="list-style-type: none">• Limited

Recommendations

The REALM is not recommended as it is interviewer administered, potentially disempowering for people with low literacy, and measures a limited range of enablement elements.

Empowering Speech Practices Scale (ESPS)

Development and validation

The ESPS, a 44-item instrument, assesses enablement in the hospital setting, from the patients' and nurses' perspectives.^{180 181} The tool is filled out by patients and nurses to assess counselling sessions for their empowering characteristics for patients.

The developers constructed the ESPS based on empowerment theory. The tool was developed in four stages: 1) a conversation analytic was developed on the empowering orientation of counselling. 2) A questionnaire was designed based on this with 65 statements and six clusters:

- Setting expectations for discussion
- Offering individualised information and advice
- Facilitating reflection
- Constructing a positive atmosphere
- Respecting and bringing up the patient's competence concerning health
- The patient's assertiveness.

The questionnaire was designed to be completed by both nurse and patient post counselling in parallel (the same statements used). At stage 3) simulated interviews were held with 5 patients and 5 nurses who watched videotaped sessions and used the tool. The tool was then modified down to 58 statements. At stage 4) the altered measurement was tested on 4 patients in a hospital ward.

The tool was tested in 17 wards and polyclinics in the Central Finland Health Care District. The construct validity was not well demonstrated (hypothesised constructs did not match the empirical constructs identified using factor analysis) and the reliability of the scales was poor (alpha 0.52-0.75).

Applicability in Australia

No studies identified outside Finland

	Related scales	Utility of scale
Physical capacity	<ul style="list-style-type: none">• Respecting and bringing up the patient's competence concerning health	
Cognitive capacity	<ul style="list-style-type: none">• Offering individualised information & advice• facilitating reflection	
Motivational capacity	<ul style="list-style-type: none">• Constructing a positive atmosphere• the patient's assertiveness	
Relational capacity	<ul style="list-style-type: none">• Setting expectations for discussion	
Overall	<ul style="list-style-type: none">• Some coverage of each domain	<ul style="list-style-type: none">• Limited information, co-administered by practitioner-patient

Recommendations

The ESPS has potentially valuable dimensions that may measure enablement. The tool required further development and testing.

Patient Empowerment Scale (PES)

Development and validation

The field of empowerment research is rapidly growing, with numerous reviews, conceptual models and new questionnaires to measure the concept¹⁸² A wide range of questionnaires have been developed in recent years yet few have been well validated and implemented.

The PES was initially generated through a review of the literature and items were constructed to cover an a priori conceptual model.¹⁸³ The scale construction approach followed an “unfolding” model by Mitchell.¹⁸⁴ Item development was also informed by in-depth interviews (n=13). Fourteen themes were identified, and operationalised as 28 statements. The scale was then applied to a pilot sample of 100 cancer patients. Responses were analysed using Rasch measurement to generate a robust unidimensional scale.

The dimensions include many indicators of enablement, which is promising, however because the tool generates a total score, the use of the tool is problematic in the health system improvement setting. The fourteen themes are:

- Information relating to illness
- Involvement in decision-making process
- Family support
- Patient perceived usefulness to family
- Complementary therapies
- Patient perception of GP ability to manage illness
- Support of friends
- Patient perceived usefulness to friends
- Paid employment
- Acceptance and adaptability to illness
- Relationship with GP
- Patient perception of health professionals' willingness to include them
- Spiritual beliefs
- Resources

Applicability in Australia

The PES, while developed in Western Australia in 2006, has rarely been used in research and has not undergone further testing. One cancer study used it as an outcome measure in a study of shared care in people with cancer.¹⁸⁵ PES, and several other psychological measures did not find any effects in the treatment group compared with controls. The tool did not identify people with low empowerment, which may have been a reflection of the items of the tool or the sample recruited.

	Related scales	Utility of scale
Physical capacity		
Cognitive capacity		
Motivational capacity	<ul style="list-style-type: none">• Empowerment (sense of control over the illness)	<ul style="list-style-type: none">• 28 statements high burden
Relational capacity		
Overall	<ul style="list-style-type: none">• Dimensions cover a wide range but appear to be organised to focus on empowerment	<ul style="list-style-type: none">• Does not seem to capture low enablement

Recommendations

Insufficient testing has been undertaken on the PES and scoring requires further work.

Patient Enablement Instrument

Development and validation

The Patient Enablement Instrument (PEI) developed in 1998 by Howie et al.¹⁸⁶ has been suggested as a measure of a clinical consultation, but going beyond patient satisfaction. The instrument focuses on the impact of a consultation on a patient's self-perceived ability to understand and cope with health issues and disease. The original PEI version was developed from literature reviews and patient interviews to evaluate enablement after a clinical consultation in primary health care. The PEI consists of 6 questions that ask patients to respond specifically to the consultation they just received with a healthcare professional. The questions are:

1. Able to cope with life
2. Able to understand your illness
3. Able to cope with your illness
4. Able to keep yourself healthy
5. Confident about your health
6. Able to help yourself

The instrument has been described to be related to, but different from, measures of satisfaction¹⁸⁶. The original PEI has been translated and evaluated in several countries, generally exhibiting high internal reliability across a range of setting including in France, China, Poland and Sweden.^{187 188 189 190 191}

The Swedish study found that a large proportion of respondents characterised at least one of the questions as irrelevant (39%). They concluded that the "PEI has high internal consistency and moderate to good reliability. It can be used in research but is not recommended as a measure of quality of care. The instrument could benefit from further development and validity testing".¹⁹¹

One of the largest studies using the PEI was in Scotland among over 3000 patients across 26 GPs within high and low socio-deprivation areas. PEI was lower in patients with multimorbidity of 3 or more long-term conditions (reflecting poor chronic general health), and those consulting about a long-standing problem.⁷²

Applicability in Australia

Two small cross-sectional research studies were undertaken by Australian authors, both were in primary care clinics and explored GP style and predictors of enablement.^{192 193} It has had limited uptake and may not have high credibility in the Australian GP setting. A further study by Desborough et al (2014) sought to generate a "Patient enablement and satisfaction survey" and combined the PEI with a satisfaction survey.¹⁹⁴ This survey is considered in detail in the next section.

	Related scales	Utility of scale
Physical capacity		
Cognitive capacity	<ul style="list-style-type: none">• Patient enablement	<ul style="list-style-type: none">• 6 simple items
Motivational capacity	<ul style="list-style-type: none">• Patient enablement	
Relational capacity		
Overall	<ul style="list-style-type: none">• Captures some elements of enablement	<ul style="list-style-type: none">• Single score, easy to apply, but focusses 'the consultation'

Recommendations

The PEI has primarily been used as a research tool to explore quality in primary care. It may not detect gaps in enablement and change over time. Not recommended.

Patient Enablement Satisfaction Survey (PESS)

Development and validation

Desborough et al.¹⁹⁴ sought to develop a survey to evaluate the satisfaction and enablement of patients receiving nursing care in Australian general practices.¹⁹⁵ They developed the PESS, a combination the PEI (discussed above) except the question about 'coping' was removed, and the Client Satisfaction Tool (CST) developed by Bear and Bowers.¹⁹⁵ These questionnaires were chosen because they were "considered a valuable foundation due to: their origins in primary health care; their acknowledgement of client singularity, central to the concept and delivery of client-focussed care; the CST for its grounding in nursing theory; and the ease with which they could be scored and applied in a variety of practice settings.¹⁹⁵ The initial development and validation included rudimentary face validity data and peer endorsement. The tool requires basic psychometric evaluation.

Question	Measure
a. The nurse/s were understanding of my personal health concerns	Affective support
b. The nurse/s gave me encouragement in regard to my health problem	
c. I felt comfortable to ask the nurse/s questions	Health information
d. My questions were answered in an individual way	
e. I was included in decision-making	Decisional control
f. I was included in the planning of my care	
g. The treatments I received were of a high quality	Professional/technical competencies
h. Decisions regarding my health care were of high quality	
i. The nurse/s were available when I needed them	Access to health care
j. The nurse appointment times were when I needed them	
k. The nurse/s spent enough time with me	Time
l. I was confident with the nurse/s' skills	Professionalism
m. The nurse/s were very professional	Overall satisfaction
n. Overall, I was satisfied with my health care	
o. The care I received from the nurse/s was of high quality	

Applicability in Australia

While the original questionnaires were developed in other countries, the adaption was undertaken in Australia. Apart from the initial development paper, only one other published study was identified and was undertaken by the creators.¹⁹⁶ This study found all patients had high satisfaction, which may be a reflection of the sample tested, the items are affected by social desirability, or are insensitive to low satisfaction levels. The tool is relatively specific to primary care nursing in Australia but could be adapted for wider application.

	Related scales*	Utility of scale
Physical capacity		
Cognitive capacity	• Partial	
Motivational capacity	• Partial	
Relational capacity		
Overall		• PHC Nursing-specific, single score.

* see PEI above. Unclear where satisfaction concepts fit across enablement concepts.

Recommendations

The PESS (that is, the PEI and CST) require further evaluation prior to wider application. They also require adaptation to settings beyond primary care nursing.

Partners in Health Scale (PIH)

Development and validation

The PIH was developed at Flinders University in 2003 to assist with chronic condition self-management practice¹⁹⁷, that is, to be used by primary health care professionals and their patients. The construction and initial conceptualisation was based a review of the literature which derived a definition of self-management that guided its development.

Self-management involves the individual working in partnership with their carer(s) and health professionals so that (s)he can:

1. Know their condition and various treatment options.
2. Negotiate a plan of care; (i.e., Care Plan).
3. Engage in activities that protect and promote health.
4. Monitor and manage the symptoms and signs of the condition(s).
5. Manage the impact of the condition on physical functioning, emotions and interpersonal relationships.

Eleven items were developed to cover all elements of the definition. It was administered to 20 patients in a pilot study and was found to have acceptable reliability and exploratory factor analysis suggested there were three factors among the 11 items.¹⁹⁷ The original tool has been cited 70 times since 2003.

A revised version was published in 2010 and included an additional item *Adopt lifestyles that promote health*. The 12 items were applied in a larger sample (n=249) of patients with a range of co-morbid chronic conditions including diabetes, cardiovascular disease and arthritis¹⁹⁸. Good internal consistency was found and exploratory factor analysis suggested four factors (knowledge, coping, management of condition and adherence to treatment) across the twelve items. A recent validation study provided further information on the PIH reliability¹⁹⁹. The authors conclude that a range of further studies are required:

"The PIH scale may help health professionals to introduce the concept of self-management to their patients and provide assessment of areas of self-management. A limitation is the narrow range of validated PIH measurement properties to date. Further research is needed to evaluate other important properties such as test-retest reliability, responsiveness over time and content validity".¹⁹⁹

<p>Knowledge</p> <ol style="list-style-type: none">1. Overall, what I know about my health condition(s) is2. Overall, what I know about my treatment, including medications for my health condition(s) is <p>Partnership in treatment</p> <ol style="list-style-type: none">3. I take medications or carry out the treatments asked by my doctor or health worker.4. I share in decisions made about my health condition(s) with my doctor or health worker.5. I am able to deal with health professionals to get the services I need that fit with my culture, values and beliefs6. I attend appointments as asked by my doctor or health worker.	<p>Recognition and management of symptoms.</p> <ol style="list-style-type: none">7. I keep track of my symptoms and early warning signs (e.g. blood sugar levels, peak flow, weight, shortness of breath, pain, sleep problems, mood)8. I take action when my early warning signs and symptoms get worse <p>Coping</p> <ol style="list-style-type: none">9. I manage the effect of my health condition(s) on my physical activity (i.e. walking, household tasks)10. I manage the effect of my health condition(s) on how I feel (i.e. my emotions and spiritual well-being)11. I manage the effect of my health condition(s) on my social life (i.e. how I mix with other people)12. Overall, I manage to live a healthy life (e.g. no smoking, moderate alcohol, healthy food, regular physical activity, manage stress)
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A validation study has also been undertaken in Mexico.²⁰⁰ The PIH scale has been included as a secondary outcome in randomised controlled trials however very few have been completed.

Applicability in Australia

The PIH was developed in Australia and has been applied in several studies and is integral to the widely applied Flinders Model of self-management support approach (www.flindersprogram.com).

	Related scales	Utility of scale
Physical capacity		
Cognitive capacity	<ul style="list-style-type: none"> • Recognition and management of symptoms, Knowledge 	
Motivational capacity	<ul style="list-style-type: none"> • Coping 	
Relational capacity	<ul style="list-style-type: none"> • Partnership in treatment 	
Overall	<ul style="list-style-type: none"> • PIH captures several aspects of enablement 	<ul style="list-style-type: none"> • Many items may not be relevant to people with low enablement

Recommendations

The PIH scale is mainly used to support the clinical-patient interaction. It was not conceptualised as an outcomes tool and is not well tested for that purpose. Recommended as a clinical decision-making tool only.

Patient Assessment of Chronic Illness Care (PACIC)

Development and validation

In 2005 a team from the Kaiser Permanente and Group Health Cooperative²⁰¹ reported on a self-report instrument to assess the extent to which patients with chronic illness receive care that aligns with the Chronic Care Model.²⁰² The tool, the Patient Assessment of Chronic Illness Care (PACIC) sought to measure whether care is patient-centred, proactive, planned and includes collaborative goal setting; problem-solving and follow-up support.

A 20-item tool was developed from 5 a priori scales based on the key components of the CCM. These subscales were hypothesised to be:

1. Patient activation;
2. Delivery system design and decision support;
3. Goal setting and tailoring;
4. Problem-solving and contextual counselling;
5. Follow-up and coordination.

The PACIC have been influential, highly cited (274 cites since 2005) and widely adapted. Initially developed in English, PACIC versions in Danish, Dutch, French, German, Slovenian and Spanish, tested in patients presenting diverse chronic diseases (e.g. diabetes, arthritis, elderly and chronic lung diseases), are available (see Iglesias et al.²⁰³ and Rick et al.²⁰⁴ for review).

The PACIC dimensions have been widely debated. In general, authors have suggested that the five hypothesised dimensions are not well represented in empirical data and users should consider working with individual items and an overall total score.^{203 204}

Applicability in Australia

The PACIC was tested in Australia²⁰⁵ within the Teamwork study, it was a cluster-randomised trial involving 60 practices in urban and rural New South Wales, Victoria and the Australian Capital Territory.²⁰⁶ This study aimed to evaluate the impact of facilitating an enhanced role for non-general practitioner (GP) staff in the management of patients with chronic illness. These were recruited from 16 Divisions of General Practice. This study did not reproduce the original five factors, rather two factors were found; (1) shared decision making and self-management, and (2) planned care (referral and follow-up). The two dimensions were discriminative enough to distinguish between respondents with a single illness and those with two or more illnesses; or low and high socioeconomic status; or good and poor general health; or longer and shorter duration of the disease. Patients with high socio-economic status (well-educated and employed) were less satisfied with care.

These data, and other international studies make it somewhat unclear how the PACIC should be used in Australia. While the items and dimensions have face validity, further work is required to understand how the tool can drive quality improvement and whether it can detect change. The PACIC is likely to be useful for understanding if, from patients' perspective, whether services and systems are in place that would support people with low enablement.

	Related scales	Utility of scale
Physical capacity		
Cognitive capacity		
Motivational capacity	<ul style="list-style-type: none">• Confidence (patient's confidence in disease management)• Concerns (about their disease management).	<ul style="list-style-type: none">• Unclear
Relational capacity		
Overall		

Recommendations

The PACIC is likely to be useful in service improvement initiatives. It focuses on the experience of care, not on patient-level enabling capabilities.

Attachment C: Evidence tables for Question 3

Table 15: Details of review articles on enablement interventions

First Author (Year) Title	Review type (search year limits) No. of studies	AMSTAR Quality Appraisal	Intervention Theme	Intervention summary	Target population/ Sample characteristics/ Setting	Outcome measures	Authors' conclusions about intervention effectiveness	Elements that make the intervention work
Dennis (2013) Do people with existing chronic conditions benefit from telephone coaching? A rapid review ⁸⁵	Rapid review (2001 - 2011) N = 30	2	Coaching	Telephone/Video phone coaching	Heterogeneous, but emphasises vulnerable groups. Community setting	Physiological, behavioural, psychological, social and healthcare service usage	For vulnerable groups, telephone coaching was found to be an effective intervention.	Planned (regular and predictable support) and unscripted (tailoring of support to individual needs) coaching interactions
Kivela (2014) The effects of health coaching on adult patients with chronic disease: A systematic review ⁸⁶	Systematic review (2009 - 2013) N = 13	9	Coaching	Coaching delivered through multiple modalities	Heterogeneous Inpatient, Outpatient and Community settings	Physiological, behavioural, psychological and social	Positive outcomes were evident	Highly trained coaches: psychologists, educated coaches, or health lifestyle coaches. Their ability to assess the treatment of chronically ill patients, identify barriers to behaviour change, set health-related goals and make realistic plans for reaching these goals by listening, asking open questions, supporting and providing feedback.

First Author (Year) Title	Review type (search year limits) No. of studies	AMSTAR Quality Appraisal	Intervention Theme	Intervention summary	Target population/ Sample characteristics/ Setting	Outcome measures	Authors' conclusions about intervention effectiveness	Elements that make the intervention work
Williams (2009) Problem based learning in chronic disease management: A review of the research ⁸¹	Systematic review (1992 – 2007) N = 7/13 (adults)	5	Cognitive-based	Interventions with a focus on Problem-Based Learning principles	Sample not specified Community setting	Physiological, behavioural, psychological and social	There are significant changes in chronic disease management among participants with diabetes, asthma, arthritis and coronary artery disease	Not discussed.
Graham (2016) A systematic review of the use of Acceptance and Commitment Therapy (ACT) in chronic disease and long-term conditions ⁸⁷	Systematic review (Up to 2015) N = 18	7	Cognitive-based	Acceptance and Commitment Therapy (ACT): Group and Individual therapy formats	Sample not specified Setting not specified	Physiological, behavioural, psychological and social	Emerging evidence of improvements in outcomes, however this was based on a very small number of studies	ACT aims to reduce the behavioural and functional influence of thinking, and foster a process called psychological flexibility

First Author (Year) Title	Review type (search year limits) No. of studies	AMSTAR Quality Appraisal	Intervention Theme	Intervention summary	Target population/ Sample characteristics/ Setting	Outcome measures	Authors' conclusions about intervention effectiveness	Elements that make the intervention work
Wildevuur (2015) Information and communication Technology-enabled Person-centred care for the "Big Five" Chronic Conditions: Scoping Review 78	Scoping review (1989 - 2013) N = 60	5	ICT	Person Centered Care (PCC) ICT interventions	Sample not specified Setting not specified, but likely to be inpatient and outpatient.	There was some evidence to suggest that ICT-PCC interventions had a positive impact on clinical and behavioural outcomes.	There was some evidence to suggest that ICT-PCC interventions had a positive impact on clinical and behavioural outcomes.	Not discussed
Pare (2010) Clinical effects of home telemonitoring in the context of diabetes, asthma, heart failure and hypertension: a systematic review 82	Systematic review (1966 - 2008) N = 62	8	ICT	Home telemonitoring	Heterogeneous Inpatient and Community settings	Physiological, behavioural, psychological, social and healthcare service usage	For patients with diabetes, asthma and hypertension, there was evidence to suggest that telemonitoring interventions led to positive improvements in outcomes	Authors attempted to identify the elements, but could not due to limitation of individual studies. Urged future research to focus on this.

First Author (Year) Title	Review type (search year limits) No. of studies	AMSTAR Quality Appraisal	Intervention Theme	Intervention summary	Target population/ Sample characteristics/ Setting	Outcome measures	Authors' conclusions about intervention effectiveness	Elements that make the intervention work
McDermott (2013) Maximizing the healthcare environment: A systematic review exploring the potential of computer technology to promote self-management of chronic illness in healthcare settings ⁸⁸	Systematic review (Up to 2012) N = 11	9	ICT	Computer-based patient self management programs	Heterogeneous "Health supported settings"	Physiological, behavioural, psychological and social	Computer-based PSMPs were superior to standard care or no care, but insufficient evidence to determine whether they were superior to standard programs	Interventions with 'complex' behavioural change techniques (BCTs) appeared more effective than those with basic techniques. Urged future research to focus on this.
Jongh (2012) Mobile phone messaging for facilitating self-management of long-term illnesses (review) ⁸⁹	Cochrane Systematic Review (1993 - 2009) N = 4	11	ICT	Mobile phone messaging	Variation in age, but other characteristics were not reported Inpatient, Outpatient and Community settings	Physiological, behavioural and healthcare service usage	Positive outcomes were evident, but long term effects, acceptability, costs and risk is unknown due to low number of studies	Providing quick and relevant information on condition, monitoring mechanism, promoting improved adherence, a channel for peer support provision enhancing self-efficacy and providing social support

First Author (Year) Title	Review type (search year limits) No. of studies	AMSTAR Quality Appraisal	Intervention Theme	Intervention summary	Target population/ Sample characteristics/ Setting	Outcome measures	Authors' conclusions about intervention effectiveness	Elements that make the intervention work
Berzins (2009) UK self-care support initiatives for older patients with long-term conditions: a review ⁸⁰	Systematic review (1997 – 2008) N = 18	5	Multiple intervention types	Interventions ranged from provision of patient education to complex self-management programs, delivered in individual to group settings	Predominantly Caucasian, female participants with arthritis or diabetes, in their 60s. Outpatient and community settings	Physiological, behavioural, psychological, social and healthcare service usage	Positive outcomes were evident, but overall effectiveness was inconclusive	Not discussed
Coster (2009) Cochrane reviews of educational and self-management interventions to guide nursing practice: a review ⁸³	Review of Cochrane Systematic Reviews (Not stated) N = 339	6	Multiple intervention types	Interventions had a focus on Education, but ranged from provision of patient education to complex self-management programs, delivered in individual to group settings	Heterogeneous Inpatient, outpatient and community settings	Physiological, behavioural, psychological, social and healthcare service usage	Positive outcomes were evident, but it is unclear what elements are working.	Authors attempted to identify the elements, but could not due to limitation of individual studies. Urged future research to focus on this.

First Author (Year) Title	Review type (search year limits) No. of studies	AMSTAR Quality Appraisal	Intervention Theme	Intervention summary	Target population/ Sample characteristics/ Setting	Outcome measures	Authors' conclusions about intervention effectiveness	Elements that make the intervention work
Siantz (2014) Chronic disease self-management interventions for adults with serious mental illness: a systematic review of the literature ⁷⁶	Systematic review (Up to 2012) N = 18	6	Multiple intervention types	Chronic disease self management interventions for people with serious mental illness and chronic disease. Multi- session educational programs emphasising knowledge and skill development.	Participants were recruited from treatment settings with serious mental illness and chronic disease	Physiological, behavioural, psychological and social	Positive outcomes were evident	Not discussed
Brady (2013) A meta-analysis of health status, health behaviours, and health care utilization outcomes of the chronic disease self-management program ⁹⁰	Systematic review (1999 - 2009) N = 23	6	Multiple intervention types	Chronic Disease Self-Management Program (CDSMP)	Predominantly Caucasian women, with an average of 12.7 years of education Outpatient and community settings	Behavioural, psychological, social and healthcare service usage	Positive outcomes were evident, but limited to small groups of English speaking persons	Self-efficacy was the hypothesised element

First Author (Year) Title	Review type (search year limits) No. of studies	AMSTAR Quality Appraisal	Intervention Theme	Intervention summary	Target population/ Sample characteristics/ Setting	Outcome measures	Authors' conclusions about intervention effectiveness	Elements that make the intervention work
Nolte (2013) A systematic review of outcomes of chronic disease self-management interventions ⁷⁷	Systematic review (1982-2006) N = 18	7	Multiple intervention types	Group format interventions (Stanford model). These interventions had to use a formal syllabus, consist of 4-10 session and did not include any exercise lesson, reinforcement techniques, individual consultations, and/or home visits.	Samples not specified Outpatient and community settings	Physiological, behavioural, psychological, social and healthcare service usage	Positive outcomes were evident, but it was concluded that only marginal benefits are observed.	Not discussed

First Author (Year) Title	Review type (search year limits) No. of studies	AMSTAR Quality Appraisal	Intervention Theme	Intervention summary	Target population/ Sample characteristics/ Setting	Outcome measures	Authors' conclusions about intervention effectiveness	Elements that make the intervention work
Quinones (2014) Educational group visits for the management of chronic health conditions: A systematic review ⁹¹	Systematic review (Up to 2013) N = 80	8	Multiple intervention types	Self-management education (information provision, skills training, adaptability) delivered through didactic education (lecture format) and experiential education (demonstrations)	Heterogeneous Inpatient, outpatient and community settings	Physiological, behavioural, psychological, social and healthcare service usage	Positive outcomes were evident, but authors explicitly state that they were short term.	Intervention delivery (e.g. group discussion and experiential learning were perhaps more effective than didactic education). Urged future research to focus on this.
Foster (2007) Self-management education programmes by lay leaders for people with chronic conditions (review) ⁸⁴	Cochrane Systematic Review (1986 - 2006) N = 17	10	Multiple intervention types	Lay-led self-management education programs for people with chronic conditions (ASMP, CDSMP and other)	Predominantly women aged between 40-65 years Inpatient, outpatient and community	Physiological, behavioural, psychological, social and healthcare service usage	Small short term positive outcomes were evident, but overall effectiveness was inconclusive	Authors attempted to identify the elements, but could not due to limitation of individual studies. Urged future research to focus on this.

First Author (Year) Title	Review type (search year limits) No. of studies	AMSTAR Quality Appraisal	Intervention Theme	Intervention summary	Target population/ Sample characteristics/ Setting	Outcome measures	Authors' conclusions about intervention effectiveness	Elements that make the intervention work
Smith (2016) Interventions for improving outcomes in patients with multimorbidity in primary care and community settings (review) ⁹²	Systematic review (Up to 2015) N = 18	10	Multiple intervention types	Interventions were predominantly focused on changing the organisation of care delivery (typically through case management or enhanced multidisciplinary team work)	Patients with multimorbidity in primary care and community settings	Physiological, behavioural, psychological, social and healthcare service usage	Positive outcomes were evident, but authors concluded that it is difficult to improve outcomes for people with multiple conditions	Targeting of interventions towards participant needs/concerns and an organised and structured healthcare delivery setting
Heo (2014) Culturally tailored interventions of chronic disease targeting Korean Americans: a systematic review ⁹³	Systematic review (1980 - 2011) N = 16	4	Tailored	Culturally tailored interventions for cancer screening, and self management of a range of chronic diseases	Predominantly Korean American women Outpatient and community settings	Physiological, behavioural, psychological and social	Positive outcomes were evident, but there was substantial variation in outcome variables and overall effectiveness was inconclusive	Providing culturally appropriate social support, through well trained and motivated community health workers that help to break down and resolve barriers

First Author (Year) Title	Review type (search year limits) No. of studies	AMSTAR Quality Appraisal	Intervention Theme	Intervention summary	Target population/ Sample characteristics/ Setting	Outcome measures	Authors' conclusions about intervention effectiveness	Elements that make the intervention work
Lauckner (2016) Peer support for people with chronic conditions in rural areas: a scoping review ⁹⁴	Scoping review (2000 - 2014) N = 10	4	Tailored	The interventions had to involve a peer support component in a rural setting. The intervention components primarily consisted of general social support and developing new skills.	Participants lived in self-identified rural areas with a range of chronic diseases, and were from specific cultural groups (two studies: African American and American Indians) Community settings	Physiological, behavioural and psychological	Positive outcomes were evident	Social connectedness (motivation to complete or participate in program activities), reducing stigma, resonance (translating information in ways that make sense to them, and/or match their particular culture) and empowerment

First Author (Year) Title	Review type (search year limits) No. of studies	AMSTAR Quality Appraisal	Intervention Theme	Intervention summary	Target population/ Sample characteristics/ Setting	Outcome measures	Authors' conclusions about intervention effectiveness	Elements that make the intervention work
Ehrlich (2016) The impact of culturally responsive self-management interventions on health outcomes for minority populations: A systematic review ⁷⁹	Systematic review (Not reported) N = 23	6	Tailored	A combination of (1) interventions that were modified to be culturally responsive and (2) interventions where there was no clear reporting of the intervention program being modified.	Culturally and ethnically diverse samples Inpatient, outpatient and community settings	Physiological, behavioural, psychological, social and healthcare service usage	Positive outcomes were evident for both groups of interventions, however there is limited evidence to suggest that cultural adaptation of self-management interventions is more effective than non-adapted interventions.	Not discussed

First Author (Year) Title	Review type (search year limits) No. of studies	AMSTAR Quality Appraisal	Intervention Theme	Intervention summary	Target population/ Sample characteristics/ Setting	Outcome measures	Authors' conclusions about intervention effectiveness	Elements that make the intervention work
Radhakrishnan (2012) The efficacy of tailored interventions for self-management outcomes of type 2 diabetes, hypertension or heart disease: A systematic review <small>95</small>	Systematic review (2001-2010) N = 10	7	Tailored	Tailored interventions - customizing an intervention to an individual's specific needs, abilities and preferences commonly delivered through the medium of telephone calls, in-person counselling at physician clinics or individuals' homes or through a combination of both mediums	Non-English speaking participants were included in 4/10 studies Outpatient settings	Behavioural and psychological	The evidence remains inconclusive about the effectiveness of tailored interventions in improving self-management behaviours	Periodic follow-up Use of technology and instantaneous feedback

First Author (Year) Title	Review type (search year limits) No. of studies	AMSTAR Quality Appraisal	Intervention Theme	Intervention summary	Target population/ Sample characteristics/ Setting	Outcome measures	Authors' conclusions about intervention effectiveness	Elements that make the intervention work
Sidhu (2014) A systematic review of lay-led group-based self-management interventions for minority ethnic populations diagnosed with long-term conditions in high-income countries ⁹⁶	Systematic review (1948 - 2013) N = 28	8	Tailored	Lay support was defined as the absence of a professional qualification, such as nursing, dietetics, medicine, teaching or social work. At least 50% of the activity had to be group-based. 10 studies reported CDSMPs and 18 reported other self-management programs.	The inclusion criteria was that at least 40% of the study population had to be from a minority ethnic group, the setting had to be a 'very high human development' country Outpatient and community settings	Physiological, behavioural and psychological	Short-term improvements, however similar outcomes were found compared to interventions designed for the general population	Ethnically matched lay people. Ethnically tailored intervention material. Ethnically specific cultural food/activities/music. Addressing emotional wellbeing.

First Author (Year) Title	Review type (search year limits) No. of studies	AMSTAR Quality Appraisal	Intervention Theme	Intervention summary	Target population/ Sample characteristics/ Setting	Outcome measures	Authors' conclusions about intervention effectiveness	Elements that make the intervention work
Goris (2013) Effectiveness of multicultural health workers in chronic disease prevention and self-management in culturally and linguistically diverse populations: a systematic literature review. ⁹⁷	Systematic review (1995 - 2010) N = 31	8	Tailored	Multicultural Health Worker (MHW) model - a member of the CALD community who is multilingual and who has received some training in health promotion, to serve as a liaison or intermediary between health and social services and the community	Disadvantaged minority populations, 77% female Outpatient and community settings	Physiological, behavioural, psychological, social and healthcare service usage	Significant improvements in participants' chronic disease prevention and self-management outcomes	Trusting relationship Shared demographic and cultural characteristics (e.g. MHWs who worked in the CALD community were able to identify with their clients and provide culturally and appropriate health education)
Coulter (2015) Personalised care planning for adults with chronic or long-term health conditions (review) ⁹⁸	Cochrane Systematic Review (Up to 2013) N = 19	11	Tailored	Personalised care planning - Collaborative process in which patients and clinicians identify and discuss problems, and develop a plan to address these	Heterogeneous Inpatient, outpatient and community settings	Physiological, behavioural, psychological, social and healthcare service usage	Small but significant improvements when compared to usual care	Understanding the factors that shape behaviour and those that might help people make the necessary adaptations to improve their health and ability to cope with illness and disability, shared decision making and clinician expertise

Attachment D: Grey literature retrieved and searched

Table 16: Grey literature - Initial Google Search

Title	Recommendations / Key Points
Health Literacy Implications for Australia ²⁰⁷	The internet poses some unique challenges when online health information is accessed by individuals with low health literacy. Yet the requirement of users to effectively evaluate the sources of health information and whether or not the information is appropriate for them is not unique to information accessed online.
Enhancing patient engagement in chronic disease self-management support initiatives in Australia: the need for an integrated approach ²⁰⁸	Implementation of self-management support initiatives by key stakeholders Government policymakers • Inclusion of self-management support in national strategic frameworks (e.g., National Service Improvement Framework) • Sharing Health Care Initiative • Australian Better Health Initiative • Early Intervention in Chronic Disease in Community Health (Victoria) • Systematic evaluation for state-based chronic disease self-management courses (Western Australia) • Medicare Benefits Schedule (chronic disease management items, Team Care Arrangements) • Self-management interventions incorporated into national clinical practice guidelines Non-government and broader community organisations • Chronic disease self-management education programs • Disease-specific information • Telephone helplines • Support groups Health care professionals and professional associations • Medicare Benefits Schedule • Self-management curricula for undergraduate medical, allied health disciplines and postgraduate ongoing professional development programs • Self-management interventions incorporated into clinical practice guidelines Health care system managers and organisations • Primary Care Partnerships (Vic) • Self-management interventions incorporated into clinical practice guidelines
The role of Australian primary health care in the prevention of chronic disease ²⁰⁹	Primary health care providers such as GPs and practice nurses have a particularly important role in the identifying, assessing at risk patients and offering brief interventions and long term follow up. Prevention requires the organisation of care within the practice as well as across different organisations. Facilitating this is an important role for Medicare Locals and needs to be incorporated into their population health planning.
Patients' knowledge of their chronic disease. The influence of socio-demographic characteristics ²¹⁰	Patient awareness of a chronic condition underpins their capacity to self-manage that condition. Supporting patients to self-manage their chronic diseases can improve health outcomes and quality of life measures. These results suggest intensive effort is required to close the gap between the health awareness of patients in the least and most disadvantaged areas of Australia. Health literacy and self-management programs could be developed using online platforms or teleconferencing facilities to access those in rural and remote Australia.

Feasibility of an intervention to enhance preventive care for people with low health literacy in primary health care ²¹¹	We found that it was feasible to screen patients for low health literacy in general practice. However, more effort is needed to train reception staff to ensure that all eligible patients are screened and those with low literacy do not opt out. The intervention had a greater impact on the recording of preventive care than on providers' approach to its delivery. Provider training on health literacy should recognise the capacity constraints faced by GPs and needs to be tailored to their approaches to preventive care. There is little research in this area and more is needed to develop optimal interventions to support providers to address the gaps in preventive care for this vulnerable group of patients.
Health coaching. Facilitating health behaviour change for chronic condition prevention self-management ²¹²	HCA Model of Health Change. Chronic condition management interventions
A framework to support self-management. Department of Health and Human Services. Tasmania ²¹³	Framework. supporting people with chronic conditions
Health Literacy in Primary Health Care ²¹⁴	all Australians at risk of developing chronic diseases
New Models of Primary and Community Care to meet the challenges of chronic disease prevention and management: a discussion paper for NHHRC ²¹⁵	Adaptation of Wagner's Chronic Illness Model key elements of the recommended model are: 1. Self-management support and improving health literacy 2. Redesign of the primary health care delivery system 3. Shared information systems 4. Decision support systems 5. Engaging the community 6. Reengineering the organisation of health care 7. Modification of primary care organisations 8. Integrated primary health care services 9. Monitoring performance and accountability
A systematic review of interventions in primary care to improve health literacy for chronic disease behavioural risk factors ²¹⁶	Group and individual interventions of varying intensity in both primary health care and community settings may all be useful in supporting sustained change in health literacy for change in behavioural risk factors. There may be scope for some tailoring of the site and type of interventions depending on which risk factor is the focus. Our findings have implications for the design of programs, as less intense interventions may be as effective as more intensive ones. There is a need for more research to evaluate which interventions are best suited to developing health literacy for individual behaviours especially in disadvantaged populations.
NSW Chronic Disease Management Program – Connecting Care in the Community Service Model 2013 ²¹⁷	The CDMP targets people with chronic disease aged 16 years and over who are at high to very high risk of hospitalisation and who may benefit from care coordination and self-management support. The target chronic diseases are: • Diabetes • Congestive Heart Failure • Coronary Artery Disease • Chronic Obstructive Pulmonary Disease • Hypertension These diseases are targeted because: • They contribute significantly to the burden of disease (including mortality and morbidity) on individuals, carers, the health system and the community. • They result in the most frequent presentations to hospitals and drive the highest healthcare costs. • Health outcomes and quality of life can be improved for people with these diseases by providing care coordination and self-management support in the community.

Disparities in multiple chronic conditions within populations ⁴³	A strategy that focuses on improving the health and healthcare of persons with MCCs is more equitable than a single-disease approach. The priority areas identified by the HHS Strategic Framework – geared towards the general population with MCCs – also have important implications for reducing disparities in MCCs within populations. Focusing on the complete spectrum of morbidity (rather than individual conditions), in which multiple illnesses and health-related needs interact, can more accurately depict the much greater impact of illness among the socially disadvantaged [60]. This paper suggests that such an effort should include better documentation of sociocultural characteristics of populations and improved understanding of the role and inter-relatedness of risk factors within distinct population groups; establishment of a strong primary care organization of services; and development of prevention and care-management interventions that are tailored to the intricate needs of populations that experience organizational, economic, and cultural barriers to effective healthcare.
Primary Health Care Advisory Group Feedback. What aspects of the current primary health care system work well for people with chronic or complex health conditions? ²¹⁸	Expanding Telehealth MBS items to include all AHPs will extend the reach of services into rural and more remote areas, addressing inequality in health care access, patient compliance and subsequent adverse health outcomes in this population and enhance the prevention, early detection and treatment of chronic diseases in Aboriginal and Torres Strait Islander people. Sharing performance information with consumers will help inform decision-making and empower self-management of their health care.
mHealth technologies for chronic disease prevention and management ²¹⁹	mHealth interventions can promote significant improvements in glycaemic control (for diabetes patients), as well as in physical activity, weight loss, and smoking cessation, among other outcomes. However, benefits appear dependent upon the characteristics of the intervention (e.g. bundle of features, use of behaviour change theories) and the specific patient population (e.g. age, digital literacy). · One important marker of the success of a mHealth intervention is its integration into healthcare as part of a service (and not as a standalone system). Improving the uptake and impact of an mHealth service will require the following elements: I) integration into a health service, ii) bundles of features to facilitate action (e.g. decision support, followed by task support), iii) application of appropriate use of theories and behavioural change strategies underpinning program design, iv) strategies employed to maintain participant interest and minimise dropout, and v) ensuring mHealth service fidelity (i.e. the accurate delivery, receipt, and enactment of the service). · Strategies to increase uptake of mHealth should address the main barriers for each stakeholder as part of this process: payers, providers and, most importantly, patients. · Relevant to Health direct Australia, opportunities may arise in providing personalisation and tailoring offered by these emerging mHealth technologies, situating these technologies in the existing ecosystem of Health direct Australia, and identifying bundles of mHealth and eHealth features that function together as a service in this ecosystem.
Effectiveness of a Personally Controlled Electronic Health Record Intervention in Older Adults with Chronic Disease ²²⁰	The results showed participants who applied PCEHR in their life had a significant improvement in perceived usefulness, perceived barriers, perceived self-efficacy, cues to action, and total likelihood to take up self-management behaviour. On the other hand, we found that there were no significant differences in perceived susceptibility and perceived severity of participants in intervention or control groups.

ACT Chronic Condition Strategy. Improving Care and Support 2013-2018 ²²¹	State wide project in ACT.
The Coordinated Veterans' Care (CVC) Program: A guide for general practice ²²²	Guide. Reference document
Telephone coaching models to support chronic disease management in multi-morbid and vulnerable populations: a rapid review ¹²⁵	The Get Healthy telephone coaching service targets those at risk of developing a chronic condition and supports them to make lifestyle changes. The Connecting Care program is aimed at those with more severe chronic conditions who are high users of hospitals. This rapid review provides an overview of the evidence for people with one chronic condition (level 1) through to those with more complex needs at level 3. Scripted interventions may be more effective for those patients with fewer co-morbidities or less complex disease such as those at level 1 where the focus is on behavioural risk factor modification.
Multi-site videoconferencing for home-based education of older people with chronic conditions: the Telehealth Literacy Project ²²³	Telehealth education is not limited to people who can read and provides the opportunity for those with low health literacy levels to receive education. Group education via videoconferencing for CDSM has been used successfully in rural Canada using multi-site healthcare facilities, home-based videoconferencing group education is acceptable for older people with chronic conditions. Older people with little computer experience can be supported to use the equipment. Using telehealth has the potential to improve access to CDSM group educations.
Multicultural Health Workers and Chronic Disease Self-Management Programs for CALD populations: a worldwide literature review ²²⁴	Show positive outcomes of use of tailor-made self-management programs and MCHWs. The lists also show that both models are used in a variety of settings all over the world.
Inquiry into Chronic Disease Prevention and Management in Primary Health Care ²²⁵	The essential Ottawa Charter principles of equity and inclusion must be incorporated all health promotion activities through 'targeted' approaches. Despite having lower population-reach and being more expensive to implement, these targeted activities are necessary to engage disadvantaged and vulnerable populations including Aboriginal people and those with mental illness.
Submission to the Primary Health Care Advisory Group Inquiry into better outcomes for people with chronic and complex health conditions through primary health care ²²⁵	Recommendation 1: Access to allied health services for people with complex needs should be dependent on individual need rather than capped. Recommendation 2: Additional resources should be made available to support use of interpreters with non-medical health professional consultations. Recommendation 3: Policy responses should be designed according to different cohorts, defined by level of risk for poor health outcomes. The system response for high risk cohorts should be high intensity, and based on best-practice approaches. Recommendation 4: Investment in improved management of established chronic disease should be complemented by investment in prevention. Recommendation 5: In line with international models, Australian primary health care should incorporate some element of capitation funding. Recommendation 6: Commonwealth and State/Territory Governments consider Victorian community health services as a prime candidate for trialling of new pooled funding models for specific cohorts.

Managing chronic disease OPITAS ²²⁶	The Health Care Homes program recommended by the Primary Health Care Advisory Group in which the Group advised: that complex, chronically ill patients be identified using risk stratification approaches; that such patients be provided with support through Health Care Homes which incorporate the following elements: – better coordinated, more comprehensive and personalised care; – empowered, engaged, satisfied and more health literate patients, families and carers; – improved access to medical care and services, including through appropriate use of non-face-to-face phone and internet based digital health options; – improved health outcomes, especially for patients who have chronic conditions; – increased continuity and safety of care, including more consistent adherence to clinical guidelines; – increased productivity of health care service providers; – increased provider satisfaction, working to full scope of their license; and – enhanced sharing of up to date health summary information. Systems provided at this level need to be as automated and as low cost as possible.
Chronic Illness Care for Aboriginal and Torres Strait Islander people: Final Report ²²⁷	Implementation research suggests that strategies to address gaps in care are more likely to be effective if they are designed to specifically address identified barriers and enablers to improvement. Development of strategies should therefore be based on best available evidence on barriers and enablers, including local knowledge, formal research evidence and theory. Improve induction, training and mentoring programs and develop associated resources and guidelines to increase skills in all areas of chronic illness care.
Chronic Disease Service Referral Pathways - health first ²²³	A tool to assist improved integration between General Practices and service providers.
Better outcomes for people with chronic and complex health conditions through primary health care – Primary Health Care Advisory Group Online Survey – APNA submission ²¹⁸	Care for people with chronic or complex health conditions needs to be tailored and coordinated on the basis of a person’s condition(s), social, work, and living environment, and other personal circumstances including carer involvement (where appropriate). There are significant advantages in preventing disease and on reducing the impact once the disease or condition has occurred. Greater use of nurse clinics can improve care for patients with chronic or complex health conditions. Nurse clinics can improve access, reduce health care costs and reduce unnecessary workloads placed on medical practitioners. Primary health care nurses are well established as care coordinators for people with chronic and complex health conditions, such as chronic heart failure and diabetes, applying prevention and management strategies that work to keep people well and out of hospital.
A systematic review of the use of Acceptance and Commitment Therapy (ACT) in chronic disease and long-term conditions ²²⁸	ACT interventions are not yet fully established for use in long-term conditions. There was some promising evidence that ACT may improve the parenting of children with long-term conditions, seizure-control in epilepsy, psychological flexibility, and possibly disease self-management/ lifestyle.

<p>Health literacy and vulnerable groups: What works? ⁷⁰</p>	<p>1. Health literacy can be enhanced and developed by improving service user interactions with health care professionals and agencies. 2. Health literacy can be enhanced and developed by improving the usability of health services. Health literacy can be enhanced and developed by improving access to accurate and appropriate health information. 4. Health literacy can be enhanced and developed by building the knowledge needed to improve the health care workforce's thinking, decision-making and practice. 5. Health literacy can be enhanced and developed by operationalising an integrated model of health literacy.</p>
<p>Better Outcomes for People with Chronic and Complex Conditions through Primary Health Care. ²²⁹</p>	<p>Local solutions within a coherent PHC policy framework will be where we can get best gains. Given the diversity of population health needs, the need for tailored and targeted service solutions for people with complex and chronic conditions, variation on workforce supply, service mix and availability regionally, the commissioning and 'system steward' roles of PHNs needs to be supported and accelerated. PHNs need to be upskilled in systemically involving consumers in all stages of the commissioning cycle and they need access to flexible funding of scale in order to respond comprehensively to the needs of this population cohort in their catchment.</p>
<p>Using Portable Health Information Kiosk to assess chronic disease burden in remote settings. Rural & Remote health ²³⁰</p>	<p>Health kiosks can be the multifaceted solution to overcome difficult obstacles when working in remote and resource-poor settings where there is poor infrastructure and a lack of qualified trained personnel. The use of health kiosks to communicate interactive health education modules created in a user-friendly interface can help to inform the populations in diverse settings about the risk factors of chronic diseases and the methods of prevention, monitoring and its management. Health kiosks can also be useful in determining a true epidemiological burden of disease conditions in remote and rural areas. Health kiosks can help to generate evidence-based, meaningful information to support key decisions for national and regional programs and policies throughout the developing world.</p>
<p>Regionally Tailored Primary Health Care Initiatives through Medicare Locals Fund ²³¹</p>	<p>Report. Planning. Policy level. Annual Plan to the Department of Health, the Medicare Local</p>
<p>Action plan early intervention & integrated care 2014 – 2017 ²³²</p>	<p>Disadvantaged & marginalised groups in the G21 region. G21 is the formal alliance of Government, business and community organisations working together to improve people's lives in the Geelong region.</p>
<p>Achieving patient-centred care: the potential and challenge of the patient-as-professional role ¹⁹⁶</p>	<p>Support exists for the patient-as-professional role. The characteristics and influencing factors identified in this study could guide patient engagement with the inter-professional team and support clinicians to provide patient-centred care. Recognition of the role has the potential to improve health-care delivery by promoting patient-centred care.</p>
<p>Victorian Primary Care Partnerships Submission to Primary Health Care Advisory Group. ²³³</p>	<p>Submission to primary health care advocacy group. Better Outcomes for People with Chronic Disease and Complex Health Conditions through Primary Health Care. Sep 2015</p>

Chapter 6 - interventions for chronic disease. Australian Atlas of Healthcare Variation Interventions for chronic disease 229	The Commission hosts a roundtable of service providers and consumers from remote areas to identify successful strategies for implementing best practice primary and secondary prevention services for patients with chronic diseases in remote Australia.
International Centre for Allied Health Evidence. Critical Appraisal Tools 234	Pamphlet with information and recommendations
Person-Centred Care and Health Literacy project website. 235	Health literacy: DE/CDEs and health professionals support health literacy through: 1. Provision of comprehensive evidence-based diabetes information 2. Shared decision making in all communications and documentation 3. Promotion of health literate services and communities 4. Evidence-based education programs. Recommendations follow for each of these areas of practice. Practitioners support person-centred care in: 1. Every episode of care and education 2. Service planning and delivery 3. Leadership
Health Literacy: A summary for Clinicians 236	Taking action to address health literacy in the work that you do can help you: 1. Communicate more effectively with your patients 2. Be confident you have all the information you need from your patient to diagnose and treat them 3. Increase the likelihood your patient will adhere to your advice around diet, physical activity, medication and other treatment regimens 4. Reduce the likelihood of your patients experiencing poorer outcomes.
Health Literacy: Taking action to improve safety and quality 237	<ul style="list-style-type: none"> • raise the profile of health literacy, including raising awareness of the roles and responsibilities of different people and organisations in addressing health literacy • reach national agreement on where and how action can be taken to address health literacy, including identifying priorities for action and opportunities for collaboration • integrate health literacy into national, state, territory, professional and other policies, programs, planning and education, including those from health, education, social and welfare sectors • examine how to best measure individual health literacy and the health literacy environment for the purposes of improvement at a local level • support healthcare organisations and healthcare providers to improve the health literacy environment, including through the provision of tools, resources, materials and leadership for action
Health literacy guide 229	The guide has a checklist for various categories of health literacy 1. Developing Patient Information 2. Assessing Patient Information 3. Improving Communication 4. Understanding Numeracy 5. Improving Numeracy 6. Improving Way-Finding
Chronic diseases in Australia the case for changing course. Background and policy paper 118	AHPC is proposing that a national action plan for chronic disease prevention be guided by four key directions: 1. Promote and implement interventions that impact early in life, as well as targeting high risk populations 2. Invest in cost-effective prevention, while innovating and building the evidence-base on what works to reduce chronic diseases 3. Measure progress on reducing chronic diseases and engender accountability for action 4. Recognise that many of the levers to prevent chronic diseases involve changes outside the health system that create healthier environments at a whole of population level

Chronic Disease Prevention and Management in Primary Care National Heart Foundation of Australia ²³⁸	Chronic disease prevention: Stop disease before it starts RECOMMENDATION 1 Provide an MBS item and blended payment to increase uptake of the 'integrated health check' (cardiovascular risk assessment, diabetes check and kidney check) to ensure people at high risk are identified and supported through on-going management. The integrated health check should also be included in the Government's proposed quality-focussed Practice Incentive Program.
Health Service Framework for Older People 2009–2016 Improving Health and Wellbeing Together ²³⁹	The Health Service Framework for Older People is set within the context of national and state based policies and strategies on ageing and associated health and wellbeing issues.
Chronic failure in primary care ²³⁹	Australian health care system is based on an outdated acute care model. Strengthening integrated care in primary care settings will particularly improve chronic disease management. Staged implementation. Service innovation and development. Performance framework. Alignment of financial incentives.
The importance of a Chronic Disease Management Program ²⁴⁰	As Private Health Fund of the Year 2014, CBHS, recognises that chronic diseases have a significant impact on the quality of life for our members. As a result, the fund offers a wide range of chronic disease management programs (CDMPs) designed to promote education and wellbeing among members who have a chronic disease or who are at risk of developing a chronic disease.
Tools for measuring change in chronic disease management in primary care ²⁴¹	Determine which aspect of practice or organisational process is most crucial to the success of a particular strategy. Some of the tools that have been outlined in this edition focus on the patient, others on the provider and yet others on teams or primary care structure and organisation of management. Prospective users are encouraged to communicate with others who have used the particular tools under consideration. Wherever possible, details and cost of the tools have been included.
Activating patients with chronic disease for self-management: comparison of self-managing patients with those managing by frequent readmissions to hospital ²⁴²	Improved understanding of the process of patient activation by more proactive clinicians could reduce the number of potentially preventable admissions.
Framework for Australian clinical quality registries ²³⁷	Australian Commission on Safety and Quality in Health Care
We're with them every step of the way. ²⁴³	Website information. Introducing Care Complete, a suite of support programs to assist GPs and their patients to better manage chronic conditions

<p>Patient centred healthcare homes in Australia: Towards successful implementation²⁴⁴</p>	<p>1. Implement a PCHCH for all applicable patients, not just those with chronic conditions 2. Engage with frontline General Practice 3. Allow adequate time for planning and preparation prior to implementation 4. Measure success against realistic process and outcome goals 5. Define and maintain the core elements of the PCHCH 6. Support adaptiveness for local conditions 7. Utilise PHNs as key implementation partners 8. Build future capacity to sustain the PCHCH approach Patient-centred Care 9. Develop marketing to establish clear mutual expectations and genuine shared accountability between patients and the PCHCH 10. Implement the necessary infrastructure and build staff capability to assess care needs and deliver care through a mix of face to face, video, phone and email consultations with all the health care team 11. Increase capacity to provide care for underserved populations 12. Enable and support patients to be active members of the health care team Collaborative, comprehensive and co-ordinated care 13. Build and fund multidisciplinary health care teams that work collaboratively at full scope of practice 14. Include preventive health, and patient life and social issues in care planning and delivery 15. Adopt a right care, right time approach 16. Recognise and work collaboratively within the wider care system 17. Build IT infrastructure and tools to support shared care planning and delivery Data driven improvement 18. Establish practice level processes for monitoring progress towards becoming a PCHCH 19. Assess and build on existing capacity to use data effectively for quality improvement 20. Focus on building take-up of evidence-based models of care Engaged leadership 21. Recognise existing leadership and actively invest in building GP leadership 22. Invest in building the capacity of the entire practice team to deliver this new model of care 23. Establish and communicate a shared vision Financing and payment paradigms 24. Ensure the payment system is designed to support achievement of the PCHCH 25. Invest in the information systems required to monitor and support new payment models (refer to doc for further recommendations)</p>
<p>Better Outcomes for people with Chronic and Complex Health Conditions.²²⁹</p>	<p>PCPs are well placed to assist local health providers to become more e-referral literate and recommend 1. Implement the Service Coordination framework across all funded health agencies and resolve issues with connectivity to ensure secure and efficient practice in relation to all aspects of service coordination: 2. Ensure a well-trained and competent workforce 3. 3. Invest sufficient resources to ensure that all agencies can meet best practice standards in relation to service coordination (refer to doc. for further info on each point)</p>
<p>Article Australian Indigenous Chronic Disease Optimisation Study (AUSI-CDS)²⁴⁵</p>	<p>Prospective Observational Cohort Study to Determine if an Established Chronic Disease Health Care Model can be Used to Deliver Better Heart Failure Care Among Remote Indigenous Australians: Proof of Concept—Study Rationale and Protocol</p>
<p>Self-management programs conducted within a practice setting: Who participates, who benefits and what can be learned?²⁴⁶</p>	<p>Positive participant outcomes can be achieved in the real life clinical setting, making efforts to implement programs worthwhile. Given consistently low referral rates through primary care physicians, efforts made to directly reach people with known chronic conditions, their families and friends are likely to be more effective than those directed toward physicians. While younger people with a positive attitude may appear to gain more, it is important to constantly encourage people from low socioeconomic status who may be disempowered (having low positive and active engagement in life) to enter these programs so that social inequalities in health are not worsened.</p>

iCAHE Outcome Calculators ²⁴⁷	The iCAHE Outcomes Calculators aim to facilitate the use of standardised outcome measures in clinical practice to monitor changes in patient status over time. Patients complete selected outcome measures prior to, or following treatment (without reference to the clinician) and the data can be entered into the iCAHE Outcomes Calculator by administrative staff. This avoids the potential bias by the clinician and ensures that the patient's view of their condition is recognised. The iCAHE Outcome Calculator automatically computes the score for each outcome measure and uses norms for comparison, as appropriate. Summarising outcomes in this way would assist in communicating patient progress, between clinicians, patients and funders.
Chronic Care Training Needs Assessment CC-TNA Tool ²⁴⁸	When focused on the role of health providers in improving chronic care we are focused primarily on their capacity to deliver quality clinical care and provide effective self-management support. Given that the CC-TNA Tool is not focused on assessing skills and knowledge related to medical and other clinical treatments for any particular chronic condition, we are primarily interested in core competencies associated with the provision of effective self-management support.
Improving the accessibility of health services in urban and regional settings for Indigenous people ²⁴⁹	The barriers to indigenous people accessing health services can be categorised as obstacles of availability (physical accessibility), affordability, appropriateness and cultural acceptability. Providing culturally secure transport. Closer to residential areas inhabited by large numbers of Aboriginal families. Home visitation. Employing salaried health professionals (as opposed to setting up a fee-for-service system). Dispensing of pharmaceuticals to clients without requiring co-payment. Using skilled multidisciplinary workforce. Allowing Indigenous people a choice between Indigenous-specific and mainstream services; employing Indigenous staff (both professionals and health workers) to bridge cultural gaps; improving the cultural understanding of health professionals; providing services in non-traditional settings; improving cross-cultural communication; and respecting cultural values such as gendered and avoidance behaviours.

Table 17: Grey literature - key organisations search

Title	Recommendations / conclusions
A rapid synthesis of the evidence on intervention supporting SM for people with long-term conditions: PRISMS ²⁵⁰	Disease management programs containing three or more components may be most effective in reducing healthcare utilization of COPD patients. Positive effects on healthcare utilization and/or healthcare expenditures may further particularly be seen in patients with less severe symptoms or over a longer period
Incentivising wellness Improving the treatment of long-term conditions ²⁵¹	potential to scale up depending on results
Asset based approaches for health improvement: redressing the balance ²⁵²	potential to scale up depending on results
A comparison of chronic illness care quality in US and UK family medicine practices ²⁵³	Enabling patients and addressing contexts Capabilities thinking can be related to some important ideas behind current interests in patient activation, enablement and empowerment. Problematic tendencies to adopt narrowly cognitive and strongly individualistic interpretations of these concepts could be countered by attention to the broad range of capabilities that can matter and the relational understanding that capabilities are situationally and socially shaped. Relational theorising about capabilities encourages an emphasis on services that respond flexibly to individuals
Beyond eligibility Universal and open access support and social care ²⁵⁴	comprehensive toolkit including templates, tools that can be taken up by any organisation
A National Telehealth and Telecare Delivery Plan for Scotland to 2015 ²⁵⁴	comprehensive toolkit including templates, tools that can be taken up by any organisation
Enabling Everyday Lives A report into occupational therapy in social services departments in Wales ²⁵⁵	Disseminate new roles and innovations and articulate how the role or service fits and enhances existing provision. 2. Promote the role of the nurses in LTC management to patients and the wider community. 3. Actively engage with service users in shaping LTC services to meet patients' needs. 4. Improve the support and supervision for nurses working within new roles. 5. Develop training and skills of nurses working in the community to enable them to take a more central role in LTC management.6. Develop organisations that are enabling of innovation and actively seek funding for initiatives that provide an environment where nurses can reach their potential in improving LTC services. 7. Work towards data systems that are compatible between sectors and groups of professionals. Explore ways of enabling patients to access data and information systems for test results and latest information. 8. Promote horizontal as well as

	vertical integration of LTC services.
Preventing hospital visits through telemedicine ²⁵⁶	Peer-support programs have the potential to improve HL and reduce health inequalities but potential is dependent upon the surrounding equity context. More explicit empirical research is needed, which establishes clearer links between peer- supported HL and health inequalities.
Innovative Care for Chronic Conditions. WHO ²⁵⁷	Recommendations for research 1. Research is needed to understand how health-service managers and staff can change the culture in their health-care organisations to enable a whole-systems approach to self-management support. 2. Most research on self-management support interventions has only short-term follow-up periods.
Primary health care as a strategy for achieving equitable care: a literature review ²⁵⁸	Recommendation: The Quality and Outcomes Framework should be overhauled so that processes measures, such as albumin testing, are recorded on an annual basis with more frequent testing for HbA1c. Additional indicators for all long-term conditions should be developed which concentrate on outcome measures. For example, in diabetes these would reward reduced numbers of people with diabetes suffering renal failure or being admitted to hospital with diabetic ketoacidosis.
A Conceptual Framework for Action on the Social Determinants of Health ²⁵⁹	An asset based approach, as presented here aims to redress the balance between evidence of effectiveness about 'what works' derived from the identification of problems (a deficit approach) to one which puts emphasis on positive attributes. Asset based approaches can jointly identify and activate solutions which promote the self-esteem of individuals and communities leading to less dependency on public services.
Preparing a health care workforce for the 21st century The challenges of chronic conditions ²⁶⁰	Following National Health Service (NHS) investment in primary care preparedness, but prior to the QOF, UK practices provided more standardised care but did not achieve better intermediate outcomes than a sample of typical US practices. US policymakers should focus on reducing variation in care documentation to ensure the effectiveness of P4P efforts while the NHS should focus on moving from process documentation to better patient outcomes.
Prevention of chronic disease. In: Guidelines for preventive activities in general practice, 8th edition ²⁶¹	Prevention and early intervention: What would 'good' look like? Policy · A comprehensive and well-articulated prevention strategy is in place, with an accompanying performance framework that is actively managed. · A Local Area Agreement is aligned to support the vision of prevention, efficiency and well-being. Interventions: · Arrangements in place to deliver the 'universal offer' (i.e. advocacy and advice services available to all to enable prevention and self-management). · Proactive approaches in place to identify older people at risk of deterioration in order to intervene early. · A comprehensive range of non-case-managed well-being services, probably commissioned from the third sector. · The mainstream application of telecare. · A reasonable volume of extra-care or supported housing. · Well functioning regalement and intermediate care services. Source: Department of Health (2009), Use of Resources in Adult Social Care. A guide for local authorities. PP 63-64.
Agency for healthcare research and quality. Best evidence statement (BEST). ²⁶²	Plan to roll out national telehealth system for people with long term conditions. Communication of health care information to patients and caregivers using multiple means
Agency for healthcare research and quality. Registered Nurses' Association of Ontario (RNAO). ²⁶³	The contribution that occupational therapists make to the Assembly Government's vision for health and wellbeing in Wales needs to be fully recognised and included in local and national policy documents.

Older people with social care needs and multiple long-term conditions. ²⁶⁴	National Institute for Health and Care Excellence (NICE) recommendation
Extending the Applicability of Clinical Practice Guidelines to Patients with Multiple Chronic Conditions ²⁶⁵	Those involved in Birmingham Own Health hope it will eventually be expanded into a national scheme, covering the whole country like NHS Direct. Information on trends in the medical outcomes of the patients enrolled in Birmingham Own Health have been used to evaluate the program and published.
A Guide to Measuring the Triple Aim: Population Health, Experience of Care, and Per Capita Cost ²³⁵	The eight essential elements for taking action are as follows: Support a Paradigm Shift Health care is organised around an acute, episodic model of care that no longer meets the needs of many patients, especially those with chronic conditions. Decreases in communicable diseases and the rapid ageing of the population have produced this mismatch between health problems and health care, and chronic conditions are on the rise. Patients, health care workers, and most importantly, decision-makers must recognise that effective chronic condition care requires a different kind of health care system. Management of chronic conditions requires lifestyle and daily behaviour change, emphasis must be upon the patient's central role and responsibility in health care. Focusing on the patient in this way constitutes an important shift in current clinical practice. To successfully manage chronic conditions, patients and families need services and support from their communities. Strategies for reducing onset and complications include early detection, increasing physical activity, reducing tobacco use, and limiting prolonged, unhealthy nutrition. Prevention should be a component of every health care interaction.
Improving the Health of Populations ²⁶⁶	Through intersectoral cooperation, they should contribute to a "Community Diagnosis", illustrating the underlying structural problems that contribute to ill health. The role of the primary health care in the process of clarifying the importance of social structures and in understanding the social determinants of health may contribute to the transformation of the social quality of the lives of individuals and communities ⁷¹ . There is a need for integration between public health and primary health care because primary health care is needed to integrate in a comprehensive way the messages and interventions from the public health approach. 5. Health systems should be organised in an intersectoral network, with cross links to environment, economy, work and education at the different institutional levels (national, province, and district). For primary health care, the full participation of the local community in the designing of services is of utmost importance, which requires a bottom-up approach. Such a primary health care system could contribute to eradication of diseases and, through its effect on social cohesion and empowerment, decrease the vulnerability of populations and strengthen communities in addressing the social determinants of health.
Does the chronic care model serve also as a temple for improving prevention ¹¹⁵	The social determinants framework developed by the CSDH differs from some others in the importance attributed to the socioeconomic-political context. This is a deliberately broad term that refers to the spectrum of factors in society that cannot be directly measured at the individual level. 'Context' therefore encompasses a broad set of structural, cultural and functional aspects of a social system whose impact on individuals tends to elude quantification but which exert a powerful formative influence on patterns of social stratification and thus on people's health opportunities.

<p>Pursuing the Triple Aim: The First 7 Years ¹²⁰</p>	<p>In addition to skills that facilitate the diagnosis and treatment of acute illness and injury, today's workforce needs a core set of competencies that will yield better outcomes for patients with chronic conditions. A workforce for the 21st century must emphasise management over cure, and long-term over episodic care. Requires the workforce to develop communication skills that empower patients through seeing health from the patient's perspective, and motivating and training patients in health-related self-management. • Solo practice is no longer adequate to achieve positive outcomes for chronic problems; the workforce must be capable of creating and maintaining partnerships with everyone involved: patients and their families, other providers and the community. • The workforce needs skills that ensure continuous quality improvement in terms of patient safety and service delivery efficiency.</p>
<p>Group Visit Starter Kit. Group Health cooperative ²³⁶</p>	<p>Benefits/Harms of Implementing the Guideline Recommendations Potential Benefits Reduced incidence and complications of chronic diseases, such as diabetes, cardiovascular disease, chronic respiratory disease, and some cancers by addressing SNAP (smoking, nutrition, alcohol, physical activity) risk factors Subgroups Most Likely to Benefit Disadvantaged people (low incomes and/or education) have higher rates of smoking and alcohol use, poorer diets and lower levels of physical activity. These higher rates are a product of social, environmental factors and individual factors, which interact. Individual behavioural counselling is most likely to be effective for patients from disadvantaged backgrounds if linked to community resources and if financial and access barriers are addressed.</p>

Table 18: Grey literature - Chronic disease self-management

Title	Recommendations / conclusions
Chronic disease SMS: the way forward for Australia ²⁶⁷	Multiple activities at all levels of a complex system are needed, including those directed at patients, carers, self-management support programs themselves, health professionals, the health system and government. Develop health literacy within the whole population. Increase engagement of patients, clinicians, and organisations with self-management programs. Priority should be given to developing programs that engage hard-to-reach patient groups, busy clinicians, and relevant organisations, so that effective self-management support is available for all people with chronic diseases, including patients who are younger, older, marginalised, culturally and linguistically diverse, from low socioeconomic groups, or who have multiple comorbidities, and carers. Programs should develop greater capacity to assess learners and tailor educational responses accordingly. System supports should increase access to programs, and flexible delivery of programs. Clinician training should include motivational interviewing approaches, with incorporation of self-management support into relevant curricula across the continuum of health professional education.
Chronic disease self-management education programs: challenges ahead ²⁶⁸	Chronic disease self-management education programs used in the Australian Government's Sharing Health Care Initiative.
CDSM: implementation with and within Australian general practice ²¹⁵	Enablers of engagement of self-management support with and in general practice • Identification of patients who may benefit from self-management support from practice records. • Development of the role of practice nurses in self-management support for patients with chronic illness. • Inclusion of negotiation of self-management support as part of patient care plans. • Inclusion of self-management support in allied health services that are provided on referral of a patient with chronic disease under a Team Care Arrangement. • Referral pathways that are sustained over time and facilitate direct communication and a continuing role for general practice staff in supporting self-management.
Evaluation of a rural chronic disease self-management program ²⁵¹	Scores on the Health Education Impact Questionnaire v2 (heiQ – RETRO) demonstrated statistically better scores at post-test on the domains of 'self-monitoring', 'insight' and 'health service navigation' with a trend towards significance on 3 other domains. The heiQ testing allowed a more precise measure of the impact of the CDSMP on participants, rating their abilities just prior to and just after participation. As the heiQ was specifically developed to measure improvements in self-management skills, this is an indicator that the CDSMP is relevant and effective in rural communities.
Common models of chronic disease self-management support A fact sheet for Primary Care Partnerships ²⁶⁹	overview from department of health perspective of chronic disease self-management models
The Flinders Chronic	The 'Flinders model' of chronic condition self-management identifies six characteristics of 'good' self-management and provides

Condition Management Program ²⁷⁰	clinicians with tools to assess self-management capability and to develop collaborative care plans with their clients.
Successful chronic disease care for Aboriginal Australians requires cultural competence ²⁷¹	A conceptual framework for chronic disease management (CDM) was developed, based on an initial broad review of the literature combined with the knowledge and relevant experience of the multidisciplinary research team
KPMG National Monitoring and Evaluation of the Indigenous Chronic Disease Package ²⁷²	Broad-based strategies are not sufficient on their own to drive the practice change required to benefit patients The ICDP embarked upon a number of broad-based strategies to improve patient care and patient management practices. These included the PIP Indigenous Health Incentive and various mechanisms to encourage primary health care organisations to implement various components of practice associated with this incentive (such as MBS Health Assessments and the provision of follow up services required by a patient).
Self-Management Support (SMS) from a Chronic Disease Worker in a Rural Primary Health Service, a Pilot Study ²⁷³	Recent contact may influence a person to respond in comparison to a patient who has not had recent contact
The RACGP Curriculum for Australian General Practice 2011. Chronic Conditions ²⁷⁴	Training outcomes of the five domains of general practice. Communication skills and the patient-doctor relationship. Use appropriate verbal and nonverbal communication techniques (e.g. open and closed questions, reflection, summarising) to gather additional history from patients and, when appropriate, family members, carers and/or other members of the multidisciplinary team, especially relating to lifestyle factors and chronic disease Use a patient centred, supportive disease management approach and develop long term relationships that help patients with chronic conditions to take as much responsibility as possible for their own health outcomes. Understand the patient's knowledge, attitudes and meaning of their illness.
A Systematic Review Of Chronic Disease Management ²⁷⁵	Self-management support, in particular patient education and motivational counselling are beneficial. Self-management support interventions are associated with improvements in disease measures, such as HbA1c in diabetes and other patient outcomes like: quality of life, health and functional status, patient satisfaction and health service use... Health professional education alone does not improve patient health outcomes. Clinical information systems that provide audit and feedback encourage the use of decision support. Health care organisations and/or community resources play significant roles in chronic disease management. There is no evidence about the role of these organisations in the literature.
Self-Management for Return to Work ²⁷⁶	Preliminary participant feedback: •regular attendees of the first program found that the training „made a difference“ in terms of: •feeling less isolated and confirming that their feelings were „normal“; •exposing them to different approaches / perspectives and ways of handling things that could improve their situations; •experience was cathartic (sharing experiences and emotions);Feedback •changed outlook (more positive); •improved management of their own situation, i.e. accepting of the system and attempting to influence aspects of their recovery that they do have control over; •fewer doubts about managing their own rehabilitation (using the resources provided and seeking help when they need it).

Use of chronic disease management software in Australia ²⁷⁷	Improvements in process parameters are likely to represent an important basis for improved health outcomes, but long-term evaluation may be needed to reveal these changes.
Get healthy information and coaching service. National Partnership Agreement on Preventive Health ²¹⁷	Evidence supports the effectiveness of telephone-based programs. Telephone counselling services can be effective in the short to medium term (3 to 6 months). Offering an intervention that is 6-12 months in duration is more effective than an intervention offered for < 6 months. Effective telephone-based programs should be individualised and based on evidence-based behavioural change theories.
Effectiveness of chronic care models: opportunities for improving healthcare practice and health outcome ²⁷⁸	The most commonly used elements of a chronic care model were self-management support and delivery system design, there were considerable variations between studies regarding what combination of elements were included as well as the way in which chronic care model elements were implemented. This meant that it was impossible to clearly identify any optimal combination of chronic care model elements that led to the reported improvements.
Enablers and barriers to the implementation of primary health care interventions for Indigenous people with chronic diseases: a systematic review ²⁷⁹	Three key features of enablers and barriers emerged from the findings: (1) they are not fixed concepts but can be positively or negatively influenced, (2) the degree to which the work of an intervention can influence an enabler or barrier varies depending on their source and (3) they are inter-related whereby a change in one may effect a change in another. From the 19 studies containing qualitative data, which included one mixed method study, 140 findings were extracted, encompassing both facilitators and barriers to the implementation of CD interventions in PHC. A list of findings extracted from included qualitative studies are shown in Additional file 4. These findings were grouped into 29 categories, which were then meta-aggregated into five synthesised findings
Factors influencing the implementation of chronic care models: A systematic literature review ²⁸⁰	this review only considered studies that included attitudes, beliefs, expectations, understandings, perceptions, experiences, resources and knowledge according to healthcare providers support (facilitators) or inhibit (barriers) the implementation of CCMs
Systematic review to inform prevention and management of chronic disease for Indigenous Australians ²⁸¹	We identified 14 systematic reviews. Seven synthesised evidence about health intervention effectiveness; four addressed chronic disease or risk factor prevalence; and six conducted critical appraisals as per current best practice. Only three reported steps to align the review with standards for ethical research with Indigenous Australians and/or capture Indigenous-specific knowledge. Most called for more high-quality research.
Living Longer Stronger Resource Kit. Aboriginal Health & Medical Research Council ²⁶⁹	Flow cart guide for health care professionals. This booklet A Practical Guide On Chronic Disease for Aboriginal Health Workers is the second resource of the Living Longer Stronger Resource Kit. The two other components of the Living Longer Stronger Resource Kit include: • Resource One (Poster): A Guide To Your Health Professionals • Resource Three (Patient booklet): A Guide To Living Longer Stronger.
Remote Health Atlas ²⁸²	It is important to empower and prepare individuals and carers to be active participants in the monitoring and management of their

	<p>chronic condition/s. It is essential for clients and families to understand their condition to engage them in their recommended care. The Health Promotion website displays health literacy resources which may assist with communicating with clients and family. The PCC Educators are able to provide assistance with recommended resources and support client education in the community, for individuals and families. 4.6.2 Chronic Conditions Care Plan The PCIS CDMP and EACS Chronic Conditions Review are multidisciplinary management plans for clients diagnosed with a chronic condition/s. These are best practice care plans that should be discussed with the client to promote their active engagement in the planned follow up. This includes a brief intervention section for SNAPE risk factors, and this presents an opportunity for timely health care intervention. See Chronic Conditions Management Plans information sheet.</p>
<p>Chronic Disease Prevention and Management in Primary Health Care August 2015 ²⁸³</p>	<p>Opportunities for the Medicare payment system to reward and encourage best practice and quality improvement in chronic disease prevention and management Multidisciplinary care Individuals with chronic disease experience better outcomes when they have access to primary health care provided by a multidisciplinary team, including a GP and one or more allied health practitioners 16-19. Currently there is a limit of five services rebated annually under the MBS for allied health (including APDs), services must be delivered face to face and there is no incentive to participate in multidisciplinary case conferencing.</p>
<p>Managing chronic disease Patients' views and attitudes to using a broadband based service ²⁸⁴</p>	<p>Cross-sectional survey consisting of an anonymous questionnaire was completed by patients whose chronic diseases were managed using the cdmNet broadband service. A convenience sample of GPs from metropolitan Melbourne (Victoria) who participated in research that included educational workshops for the purpose of upskilling GPs in the use of cdmNet were invited to be involved and invite their patients to be involved.</p>
<p>Flinders Chronic Condition Management Program ²⁷⁰</p>	<p>Self-paced online learning in Flinders Program™ courses: • Chronic Condition Management • Flinders Closing the Gap Program™ • Living Well, Smoke Free Program</p>
<p>Health Assessments and Chronic Disease Management finding your way through the maze ²⁸⁵</p>	<p>flow chart for practitioners</p>
<p>Twelve Evidence-Based Principles for Implementing Self-Management Support in Primary Care ²⁸⁶</p>	<p>1. Brief Targeted Assessment to Guide SMS. 2. Information Alone Is Insufficient to Improve Patient Outcomes: 3. Use of a Nonjudgmental Approach: 4. Collaborative Priority and Goal Setting: 5. Collaborative Problem Solving 6. SMS by Diverse Providers 7. Self-Management Interventions Delivered by Diverse Formats. 8. Patient Self-Efficacy: 9. Active Follow-Up: 10. Guideline-Based Case Management for Selected Patients: 11. Linkages to Evidence-Based Community Programs: 12. Multifaceted Interventions</p>
<p>State wide evaluation NSW Health Chronic Disease Management Program ²⁸⁷</p>	<p>LHDs moved some way towards making the CDMP part of a system of care, with clear entry points, arrange of options for care, ongoing assessment of people in the Program and processes for escalation or re-entry for those no longer receiving active support. However in most cases this was still in progress.</p>

Table 19: Grey literature: Enablement tools

Title	Recommendations / conclusions
Reliability and applicability of the Patient Enablement Instrument (PEI) in a Swedish general practice setting ¹⁹¹	It can be used in research but is not recommended as a measure of quality of care. The instrument could benefit from further development and validity testing.
Evaluation of patient with chronic disease using PACIC ²³⁸	Improving the interaction between patients and health care providers go a long way in increasing patients level of enablement. The Patient Assessment of Chronic Illness Care questionnaire (PACIC) demonstrated an excellent tool for evaluating patients perspective on received healthcare
A pilot study on the validity and reliability of the Patient Enablement Instrument (PEI) in a Chinese population ¹⁸⁸	Further studies should be carried out to evaluate the relationship between PEI scores and other external criteria to confirm its construct validity as well as to further examine determinants of patient enablement. Sensitivity in differentiating consultation outcomes in different settings or morbidity groups and responsiveness to changes with intervention will also need to be established.
Impact of nursing care in Australian general practice on the quality of care: A pilot of the Patient Enablement and Satisfaction Survey (PESS) ¹⁹⁶	This pilot indicated that the PESS can distinguish between two aspects of the quality of nursing care (i.e. satisfaction and enablement) that may impact on patient outcomes. These findings add to previous evidence validating the presence of nurses in general practice, highlighting the value they bring to patients.
Quality of care measures in multimorbidity ²⁴⁴	There has been a reliance on measures of process and outcome for single conditions in the assessment of quality of care. A broader, more comprehensive range of measures of structure, process and outcome is needed to fully evaluate the care of patients with multimorbidity.
Supporting Patient Behaviour Change: Approaches Used by Primary Care Clinicians Whose Patients Have an Increase in Activation Levels ²⁸⁸	The relationship between the clinician strategies identified in the study and both patient behaviour change and activation change should be tested in a larger sample of clinicians in order to validate the study's findings. It is inefficient for each clinician to use trial and error to find workable strategies.
Patient-centred care in chronic disease management: A thematic analysis of the literature in family medicine ²⁸⁹	Chronic disease management requires coordinated action by the patient and the physician to create a real partnership. A rich knowledge of the patient is a necessary step toward this. Patients need their concerns, ambivalence and grief over their prior capabilities to be acknowledged. The physician should provide hope and support and believe in the patient's capacity. The physician can also play a role in guiding the patient through the system. The patient will have fluctuating needs requiring physicians to adapt their role over time.
Implementation of self-management support for long term conditions in routine primary care settings: cluster randomised controlled trial ²⁹⁰	Embedding self-management support into routine primary care practice cannot be achieved within existing educational structures and may require considerable additional incentives to encourage practices to engage with a self-management agenda. Greater efforts to integrate support for self-management into patients' personal social networks (family, friends, and other social groups) or using means that are more pervasive in people's lives, such as mobile technology, would prove a more effective approach to engaging patients with self-management

	and the behaviour changes necessary to that end.
Population health enablement ²⁹¹	The key to improving population health is building a deep understanding of patterns of health, disease and wellbeing at the heart of this effort is data management and analytics. We provide data architecture and management expertise, clinical data integration and population health management consulting services. In addition, we further enable population health management through the integration of tools from our strategic partners.
DEFINE Table of Associated Measurement Tools ²³²	PDF table. PATIENT LEVEL: informed and activated patient to manage both the medical and non-medical determinants of health including health status and well-being, health behaviours, and personal resources
Patient-Empowering Care Management Workgroup: Topic Brief ²⁹²	Notes from work group meeting. There is significant opportunity to conduct new research on PECM that focuses on outcomes that matter to patients and caregivers. However, the difficulties related to culture change in practice, resource restrictions, and other barriers to implementation must be taken into consideration. Research that includes strategies for adoption of successful patient-empowering care models in practice has the greatest potential for widespread implementation. While some models of care management show success in improving patient-centred outcomes, little is known about what aspects of models work best for specific patient subpopulations. There is a need to develop measures and models related to this way of providing care By bringing together researchers, practitioners, patients, and caregivers we can establish a common set of definitions so that discussions can involve all stakeholders.
Patient focused care using the right tools ²⁹³	Patients are more likely to be motivated to follow treatment advice if they perceive the recommendations to be a common sense approach to maintaining health, and if they have a clear appreciation of the nature of their illness and an understanding of treatment risks and benefits. It is also important to consider that the management of chronic disease differs from that of an acute illness, so clinicians must be prepared to work in an ongoing partnership with patients to ensure that they are offered a clear rationale as to why medication is necessary, and to address possible adverse effects.
Why Patients Should Be More Empowered: A European Perspective on Lessons Learned in the Management of Diabetes ²⁹⁴	Establish patient empowerment and self-management of chronic diseases as a priority of the new commission's work program and position these topics at the centre of all relevant EU health policy initiatives. • Introduce EU-wide care models for chronic diseases that include behavioural and educational programs that enable patients to take responsibility and manage their condition. • Ensure that core models and recommendations for health technology assessments (HTAs) currently developed at EU level follow predictable, common criteria and methodologies which take into account the actual patient self-management activity in the investigated treatment procedure.
Empowering patients through eHealth: a case report of a pan-European project ²⁹⁵	The first lesson learnt is about how EC-funded projects should develop cumulative knowledge by avoiding self-crafted measures of outcome and by adopting literature-grounded definitions and scales. The second lesson learnt is about how EC-funded projects should identify ambitious, cross-pilot policy and research questions that allow pooling of data from across heterogeneous experiences even if a multi-centre study design was not agreed

	<p>before. The third lesson learnt is about how EC-funded projects should open their collections of data and make them freely-accessible to the scientific community shortly after the conclusion of the project in order to guarantee the replicability of results and conclusions. Summary: The three lessons might provide original elements for fuelling the ongoing debate about the capability of the EC to develop evidence-based policies by pooling evidence from heterogeneous, local experiences.</p>
<p>Managing patients with multimorbidity in primary care.²⁹⁶</p>	<p>Consider adopting a practice policy of routine extended consultations for particularly complex patients or introducing occasional “specific extended consultations,” allowing protected time to deal with problems encountered in the management of chronic diseases Ensure practice systems are in place to maximise the value of the general practice consultation for both patient and doctor in reaching management decisions—for example, by seeing the practice nurse ahead of an appointment with the doctor Arrange multidisciplinary team involvement, where appropriate. Promoting patient centred care Shared decision making. Plan regular reviews (at least annually) of drugs. Identify patients as having complex multimorbidity and adopt a practice policy of continuity of care by assigning them a named doctor</p>
<p>Review of Chronic Disease Management Local Enhanced Services Programme in NHS GGC January 2014¹¹³</p>	<p>Recommendation 1: The CDM redesign programme initiated in 2012 should continue to improve the following six elements: I. Workforce expertise and skill ii. Computerised decision support with strong MCN input iii. High quality, coordinated education and support to patients iv. CDM care delivery in primary care as part of a wider, coordinated programme v. Continuous audit and quality improvement to inform workforce support needs vi. Tackle variations in performance using approaches such as the ‘critical control point’ analysis used in Keep Well and NW COPD work Recommendation 2: The size and characteristics of additional population subgroups (beyond the current set of five chronic diseases) who would benefit most from structured CDM should be defined, explicitly prioritising conditions that make the biggest contribution to our total burden of disease and where potential interventions have strong evidence of clinical and cost effectiveness. Recommendation 3: Risk stratification should guide prioritisation of patients who require more frequent or intensive CDM, recognising significant caveats around risk stratification as a healthcare strategy. Recommendation 4: The CDM programme delivered in primary care should be integrated into a programme of accessible, clinically effective and evidence based community services Recommendation 5: A coherent, functioning ‘whole system’ service directory should be established to support consistent delivery of CDM across primary, secondary, social care and other community services. Recommendation 6: Irrespective of future developments and changes in GMS contracting arrangements, the elements of high quality CDM, as outlined in the above recommendations, should be implemented</p>

Table 20: Grey literature - Chronic and complex conditions

Title	Recommendations / conclusions
Primary Health Care in Australia A nursing and midwifery consensus view ²⁹⁷	1. Centre health policy in Australia around primary health care for people throughout their lives. 2. Invest in 'health' by funding health promotion and the prevention of illness and injury. 3. Ensure primary health care funding is based on the demonstration of positive health outcomes. 4. Fund acute health care equitably and sustainably. 5. Establish respectful partnerships between communities and individuals and health care providers, managers, researchers and educators. 6. Ensure citizens and others living in Australia participate individually and collectively in the planning and implementation of their health care in a collaborative way. 7. Acknowledge the skills, knowledge and experience of all health professionals, including nurses and midwives and use these in effective transdisciplinary teams. 8. Invest in transdisciplinary education and research for the health workforce. 9. Work closely with the non-health organisations and agencies responsible for services that can determine the health status of individual people and communities. 10. Focus on the quality and safety of primary health care.
Osteoarthritis Chronic Care Program Model of Care ²⁹⁸	To develop and adopt dynamic and flexible policy and procedures to guide implementation of the model at a local level – OACCP Site Manual.
The Association of Types of Training and Practice Settings with Doctors' Empathy and Patient Enablement among Patients with Chronic Illness in Hong Kong ²⁹⁹	Training in family medicine for doctors as well as organization of practice system to allow optimal consultation time may be conducive to quality care for patients with chronic illness.
A Conceptual Framework for Action on the Social Determinants of Health ²⁵⁹	Interventions and policies to reduce health inequities must not limit themselves to intermediary determinants, but must include policies crafted to tackle structural determinants.
A comprehensive health service evaluation and monitoring framework ³⁰⁰	Ultimately the health outcomes of the community are dependent on the socioeconomic determinants of health and the extent to which these can be addressed at a community level will determine the long term health outcomes. This requires the fundamental enablement of strong local community leadership and readiness for change empowered by supportive Commonwealth and State policy.
A cluster randomised controlled trial of the clinical and cost-	If the 'whole systems' model proves effective and cost-effective, it will provide decision-makers with a model for the delivery of self-management support for populations with long-term conditions that can be implemented widely to maximise 'reach' across the wider patient population.

effectiveness of a 'whole systems' model of self-management support for the management of long-term conditions in primary care ³⁰¹	
Measuring empathic, person-centred communication in primary care nurses ³⁰²	Research shows that an emphatic, person-centred approach to care is linked with improved experiences of care, higher patient enablement and better health outcomes. The CARE Measure appears relevant to, valid and reliable in routine practice nurse consultations.
Self-care and Case Management in Long-term Conditions ³⁰³	Collection and analysis of the data described in this report took a mixed methods approach comprising three elements: a survey relating to self-care and case management arrangements; interviews and focus groups in four case study sites; and comparison of the survey data with previous survey data
Consumers, the health system and health literacy. Taking action to improve safety and quality ³⁰⁴	Health literacy is a complex field, and this paper provides an overview of the concept, identifies where action can be taken to address health literacy in a coordinated way, and who has a role in doing this. This paper can be used by policy makers, clinicians, managers and consumers to increase their knowledge about health literacy, and inform their decision-making about what they, and their organisations, could do to address health literacy.
Managing patients with multimorbidity in primary care ²⁹⁶	Clinical review - What can be achieved in a 10 minute consultation? With demand for general practitioner services increasing, it is difficult to schedule extra consultation time for patients with multimorbidity. Practices may decide to flag certain patients with complex needs to allocate longer routine consultation times, or arrange "specific extended consultations" to allow protected time on occasion to review chronic disease management and drugs. Having robust practice systems in place to ensure appropriate monitoring with the practice nurse before the appointment with a general practitioner would facilitate the most efficient and effective use of both patients' and doctors' time. Practice nurses or other multidisciplinary team members can contribute in specific ways, including undertaking target assessment of chronic disease and psychological or functional capacity assessments that can support doctor and patient shared decision making. Multidisciplinary input is an essential component of care for these patients, and referrals to relevant disciplines should be arranged when indicated and available.
Improving care for long term conditions. Reading list ²³¹	Reading list only. This reading list is produced by The King's Fund Information and Library Service. The items on this list are selected only from items held by the Information and Library Service or are freely available on the Internet. It does not aim to be comprehensive, or to be a 'recommended reading list.

EMCDDA insights, models of addiction ³⁰⁵	Social theories surrounding addiction
Patient Outcomes at 26 Months in the Patient-Centered Medical Home National Demonstration Project ³⁰⁶	Implementation of PCMH components, whether by facilitation or practice self-direction, was associated with small improvements in condition-specific quality of care but not patient experience. PCMH models that call for practice change without altering the broader delivery system may not achieve their intended results, at least in the short term.
The CARE Plus study ³⁰⁷	The CARE Plus study – a whole-system intervention to improve quality of life of primary care patients with multimorbidity in areas of high socioeconomic deprivation Enhancing primary care through a whole-system approach may be a cost-effective way to protect quality of life for multimorbid patients in deprived areas
Prospects For Rebuilding Primary Care Using The Patient-Centered Medical Home ³⁰⁸	Requires effective policies in 1) payment reform, 2) certification of medical homes, 3) facilitating transformation of existing practices, and 4) identifying the appropriate linkages of the medical home to the rest of the delivery system.
Success and failure in integrated models of nursing for long term conditions ³⁰⁹	Nurses are making a major contribution to meeting the policy objectives for long term conditions. The scope of the nursing roles and services studied were idiosyncratic, opportunistic and reactive, rather than planned and commissioned on an analysis of local population need.
Patient empowerment in long-term conditions- PCORI ³¹⁰	There is a need to develop measures and models related to this way of providing care. Research that includes strategies for adoption of successful patient-empowering care models in practice has the greatest potential for widespread implementation.

Table 21: Grey literature - Determinants of enablement

Title	Recommendations / conclusions
Haringey Health & Social Value Checklist for social value commissioning ³¹¹	Checklist for clinicians. people living in the Borough of Haringey
Dynamics of doctor patient relationship; a cross sectional study on concordance, trust and patient enablement ²⁷⁰	Lower SES patients benefited more from consultations with doctors compared to those in a higher SES group
Is 'Close the Gap' a useful approach to improving the health and wellbeing of Indigenous Australians? ¹²⁴	Evidence from health research shows that social and structural conditions are as influential on the health of a population as are the behaviours and characteristics of the individuals of which the population is comprised. The problematic nature of the Close the Gap approach lies firstly in its predominantly individualistic focus, which fails to account for an imbalanced distribution of power and a limited degree of control exercised by Aboriginal and Torres Strait Islander Australians (both individually and collectively) over their own circumstances.
North Somerset Prevention and Early Intervention Strategy for Adults and Older People. 2015 - 2020 ³¹²	Primary prevention interventions: Advice; information; emotional support; practical help; exercise opportunities; classes; holiday opportunities; leisure activities; education; diet; help to stop smoking; housing; oral health; immunisation; health screening. Secondary prevention interventions: Specific education; relearning skills; maintaining skills; practical support; floating support; social interaction; equipment; home check; shopping; cleaning; meals; gardening; dog walking; activities; childcare; financial advice; transport; social opportunities; medical advice; medical prompts; dressings; routine prompts.
Patient enablement requires physician empathy: a cross-sectional study of general practice consultations in areas of high and low socioeconomic deprivation in Scotland ⁷²	The patients' perceptions of the doctors' empathy is of key importance in patient enablement in general practice consultations in both high and low deprivation settings. Enablement is lower in patients with multimorbidity (of 3 or more conditions) and for those consulting about a long-standing problem. In deprived areas, psychological distress has an additional negative influence. Ways of supporting and improving practitioner empathy may be crucial in enhancing patient enablement, especially in high deprivation areas, where the burden of multimorbidity, mental illness, and poor health is greatest.
Primary care and equity in health: the importance to effectiveness and equity of representativeness to peoples' needs ⁶²	Clinical settings must be designed ("structure") to achieve at least the following to provide the basis for effective services: specification of the population eligible to receive services and for whom there is accountability to provide needed services; continuity of care by means of personnel and records to facilitate transfer of important information about patients and their problems; accessibility of services, and a broad enough range of services to meet all health-related needs in the population except those that are too uncommon to maintain competence.

<p>We've Got To Talk About Outcomes. Rethinking Enablement The Enabling Potential of Outcomes Focused Working ³¹³</p>	<p>The growing policy emphasis on enablement has resulted in a greater emphasis on the measurement of enablement and the related concept of patient activation in a number of healthcare services. Given the importance of enablement in policy and practice, and the limitations of current measures in some care settings, the Project findings suggest the need for a more robust investigation into this possibility. In policy terms, enablement and the related concept of empowerment are thus broadly concerned with supporting people to access, use and further develop their strengths, diverse capabilities and rights to lead fuller lives.</p>
<p>Supporting people in the Royal Borough to maintain their health and independence. ⁶³</p>	<p>Recommendations include: - preventing admissions in the first place, by using 'frailty' indicators and screening to trigger a comprehensive geriatric assessment and care planning, with emergency pathways and access to multidisciplinary teams for treatment and therapies at home - assertively managing the health and care needs of people with dementia to keep them out of hospital - early, 'front-end' assessment on admission to hospital, with community services available 7 days a week to 'pull' people out of hospital - electronic access to information about people across health and social care to expedite care planning - regular review of people having a prolonged stay in hospital (including community hospitals), to agree action for the person and identify trends, involving hospital and community health staff, and social care - early involvement of community staff (health and social care) in planning with the hospital for a person's discharge, ideally implementing a plan that was developed with the person before they were admitted - simple and rapid processes for referral, initiation and funding of care packages - promoting cultural change and improvements to hospital-based care for people with dementia - developing programmes to reduce risk of admission from care homes and enhance staff competencies - gathering patient and carer feedback, and auditing discharges and re-admissions to learn and share what needs to be improved.</p>
<p>The inclusion of migrants in health impact assessments: A scoping review ³¹⁴</p>	<p>Although workshops and stakeholder engagement were a frequent way of including migrants in HIAs, this usually involved organizations representing migrants, and only seldom included members of the migrant community themselves. The main barriers to including migrants in the HIA impact analysis were the lack of available data on migrants and the significant additional resources required to gather and analyse additional data on migrants. Guidance is needed on ways to optimally include migrants in HIAs and ensure that recommendations for mitigation measures are optimal.</p>

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