Evidence:

Helping people help themselves

The Health Foundation
Inspiring Improvement

A review of the evidence considering whether it is worthwhile to support self-management

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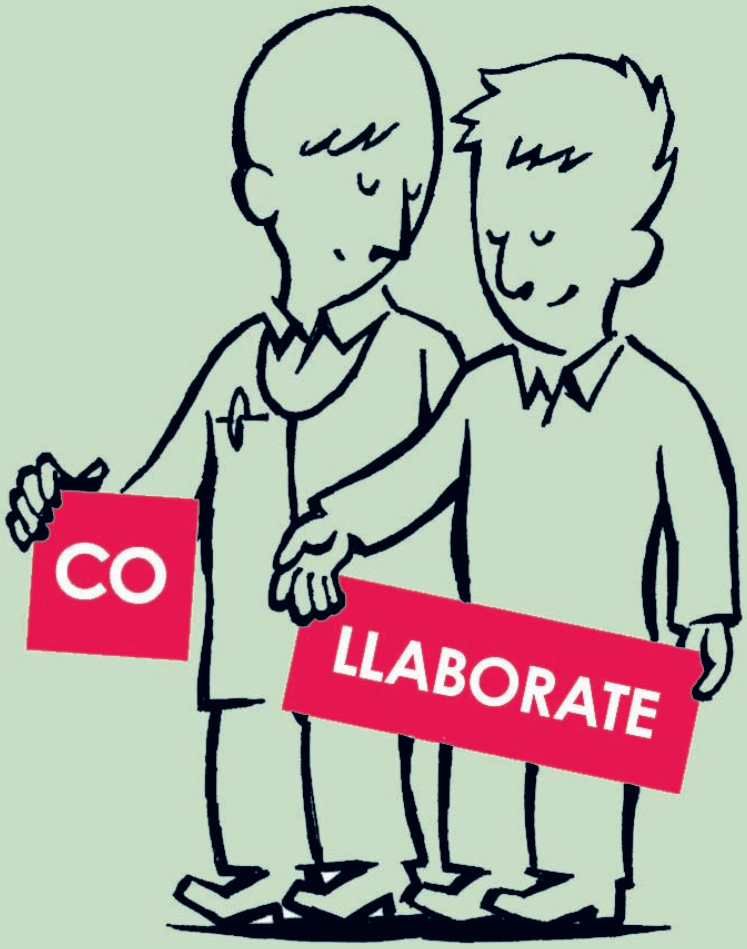

Identify Innovate Demonstrate Encourage

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Foreword

When it comes to putting self-management support at the heart of routine healthcare, there is a huge gulf between political rhetoric and the reality of UK clinical practice. Many clinicians question the notion that their role should change to support self-management. Why should clinical practice change? What is the evidence that self-management support works?

The Health Foundation has produced this literature review to respond to the questions and challenges of clinicians wanting to appraise the benefits of self-management support. The literature shows that proactive, behaviourally focused self-management support designed to increase self-efficacy can have a positive impact on people's clinical symptoms, attitudes and behaviours, quality of life and patterns of healthcare resource use. This echoes the experience of the hundreds of clinicians and patients across the UK that have been involved in Co-creating Health, our demonstration programme to test the implementation of strategies for embedding self-management into routine care. Our independent evaluation of the programme will report in 2011.

So what is to be done? Two conclusions of this review stand out. First, it provides a new perspective on self-management support. Traditionally, a wide range of methods have been described as supporting self-management – interventions as varied as handing out leaflets, tele-monitoring, intensive telephone coaching and structured education. This review shows that some approaches are significantly more effective than others.

Thus, it is essential that healthcare providers critically appraise this evidence and focus efforts on those methods with the strongest evidence.

Second, it shows that proactively supporting self-management and focusing on behaviour change can have an impact, in some circumstances, on clinical outcomes and emergency service use. Furthermore a focus on behaviour change is a necessary component in facilitating the effectiveness of other methods such as information provision.

The review reminds us that self-management support is still in its infancy. While there is a growing research base, we know much less about how to replicate the positive results produced in research contexts in real-world healthcare. We need many more opportunities, like those provided by Co-creating Health, that allow healthcare professionals and system leaders to explore the best ways to make self-management support a part of routine healthcare.

The UK healthcare system can't afford to ignore this evidence. Already the 30% of the population with long term conditions accounts for 70% of NHS spending. Reducing people's dependence on health professionals and increasing their sense of control and wellbeing is a more intelligent and effective way of working.

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Executive summary

Self-management works

This review of more than 550 pieces of high quality research suggests that it is worthwhile to support self-management, in particular through focusing on behaviour change and supporting self-efficacy.

Hundreds of systematic reviews, randomised controlled trials and large observational studies have examined the impact of supporting self-management for people with long term conditions. Whilst the findings of individual studies are mixed, the totality of evidence suggests that supporting self-management can have benefits for people's attitudes and behaviours, quality of life, clinical symptoms and use of healthcare resources.

Some suggest that the evidence for supporting self-management is only moderate but this is because a wide range of activity is described as 'self-management support' and some interventions may be more effective than others. Past reviews have tended to combine initiatives that focus solely on information provision with interventions that more actively target behaviour change and self-efficacy. However, these varying interventions may have different outcomes so combining them could dilute the findings.

Supporting self-management has the potential to alleviate the pressure on health and social services caused by workforce shortages, rising demand for services, population increases and budgetary constraints. However, implementing one off interventions is unlikely to make a significant impact on the overall health of the population or on the sustainability of health and social care systems.

Supporting self-management is not a panacea, and is likely to work best when implemented as part of wider initiatives to improve care through educating practitioners, applying best evidence, and using technology, decision aids and community partnerships effectively.

Proactive strategies work best

There are a wide range of initiatives to support self-management. These can be categorised along a continuum of interventions, with passive information provision about healthy behaviours and other 'technical' topics at one end of the scale and initiatives that more actively seek to support behaviour change and increase self-efficacy at the other end of the continuum.

Different clinical conditions may require varying approaches to support self-management. For instance, people with conditions such as diabetes may benefit from structured education about how to eat, exercise and take medications. For conditions such as depression or chronic pain on the other hand, less 'technical' or clinical education may be needed because the service user has less 'technical work' to do.[1] Therefore, evidence about self-management support for these groups tends to focus on cognitive and behavioural interventions. Such interventions may be equally valuable for people with diabetes and other conditions, even though the focus to date has been mainly 'technical'.[2–4]

All of the different types of support are important components of the jigsaw needed to encourage self-management, but information provision alone is unlikely to be sufficient to motivate sustainable behaviour change and improve clinical outcomes. More active goal setting and behavioural change interventions are necessary. There is also emerging evidence that strategies co-created by service users and professionals or co-led by service users have positive outcomes.[5–7]

> *A co-created teaching approach better meets the learning needs of adults with type 2 diabetes mellitus and results in enhanced ability to perform the self-care activities required for successful diabetes control.*[8]

Evidence is developing

Knowledge in this area is developing so evidence about the best strategies to support behaviour change may be limited at this stage,[9–10] though much work suggests that in order to change behaviour, people need to really want to change.[11]

General components that have been found to work well to support self-management include:[12–27]

- involving people in decision making
- emphasising problem solving
- developing care plans as a partnership between service users and professionals
- setting goals and following up on the extent to which these are achieved over time
- promoting healthy lifestyles and educating people about their conditions and how to self-manage
- motivating people to self-manage using targeted approaches and structured information and support
- helping people to monitor their symptoms and know when to take appropriate action
- helping people to manage the social, emotional and physical impacts of their conditions
- proactive follow up
- providing opportunities to share and learn from other service users.

However, the best strategies for implementing these principles and the related barriers and facilitators remain uncertain.[28] There is a need for high-quality research and evaluation that focuses on building relationships between service users and practitioners and exploring the most effective strategies for encouraging behaviour change.[29]

Another core component of supporting self-management is enabling and encouraging clinicians and lay trainers to work with people to improve their motivation to change.[30] It is important to understand the skills that clinicians need to help people make changes and the barriers that may stop them from offering such support.[31–33]

Whilst evidence is emerging, there is still a long way to go before we understand the education and support necessary to optimise clinicians' attitudes, skills and behaviours towards self-management.[34] This also calls for a fundamental shift in power dynamics and the way both patients and professionals view their roles.[35–37]

> *Self-management support is the assistance caregivers give patients with chronic disease in order to encourage daily decisions that improve health related behaviors and clinical outcomes. Self-management support can be viewed in two ways: as a portfolio of techniques and tools that help patients choose healthy behaviours; and a fundamental transformation of the patient–caregiver relationship into a collaborative partnership.*[38]

Some suggest that training strategies need to account for practitioners' stage of change as well as that of patients.[39]

In order to do this we need to understand more about how best to increase self-efficacy and encourage behaviour change, and how we can motivate all members of the team, including clinicians and patients themselves, to be part of this.

Key messages

An increasing number of people are living with long term health conditions which they manage most of the time by themselves. Helping people to better care for themselves can improve their physical and mental wellbeing and change how they use services. There is good evidence that supporting self-management works.

What is self-management?

As the population ages and our lifestyles and habits change, more and more people are living with long term conditions that cannot currently be cured. In the UK more than 17 million adults have a long term condition such as diabetes, asthma, heart failure, arthritis dementia or depression.[40]

Health and social care services support people with long term conditions by providing equipment, specialist staff and medicines to control symptoms. In fact, it is estimated that about two thirds of all healthcare resources are spent supporting people with long term conditions.[41]

Even so, 80% to 90% of all care for people with long term conditions is undertaken by patients themselves and their families.[42] This self-management or self-care includes eating well, exercising, taking medicines, keeping in good mental health, watching for changes, coping if symptoms worsen and knowing when to seek professional help.

Supporting self-management involves educating people about their condition and care and motivating them to care for themselves better.

Self-management support can be viewed in two ways: as a portfolio of techniques and tools that help patients choose healthy behaviours; and a fundamental transformation of the patient–caregiver relationship into a collaborative partnership.[43]

Does self-management work?

Planners and practitioners increasingly recognise the benefits of supporting people to manage their own conditions. This rapid review compiles research about supporting self-management.

Based on the results of almost 600 studies published in the UK and internationally, there is evidence that supporting self-management can improve people's quality of life, clinical outcomes and health service use. Research suggests that proactively supporting self-management and focusing on self-efficacy (a person's confidence about looking after themselves) and behaviour change can have an impact on clinical outcomes and emergency service use.

Some studies suggest that the evidence for supporting self-management is only moderate but this is because a wide range of initiatives are described as 'self-management support' and some may be more effective than others. It would dilute the findings to combine initiatives that focus solely on information provision with interventions that target behaviour change and self-efficacy.

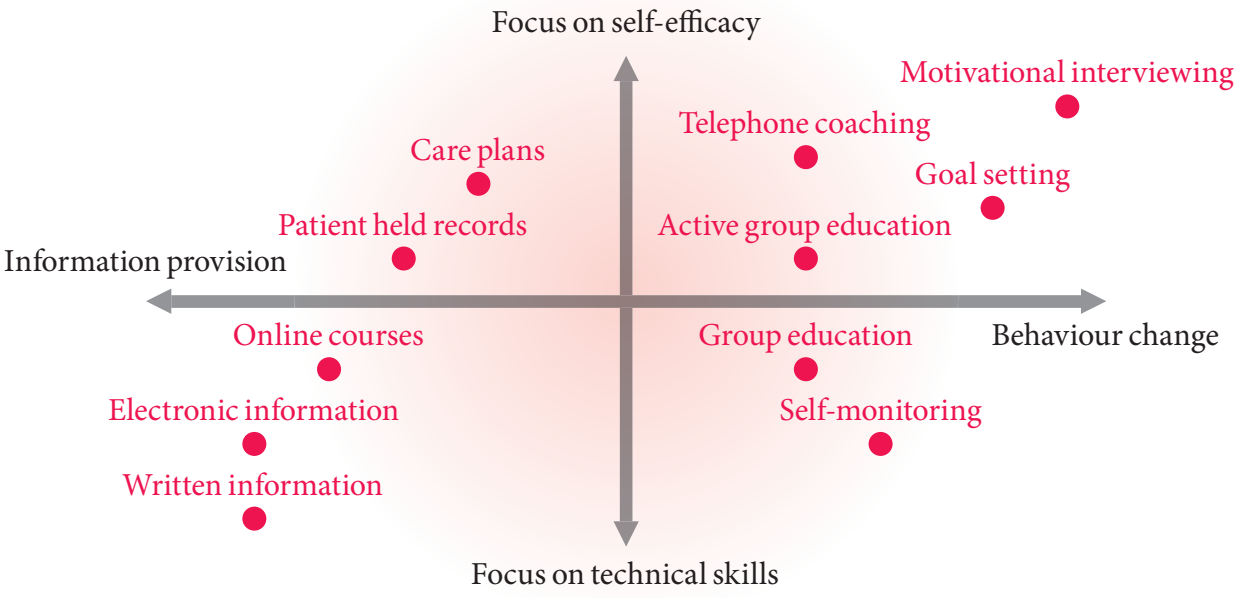
Some studies argue that supporting self-management reduces the use and costs of health services. However this focus may be too simplistic. It is more likely that patterns of service use change rather than reduce overall. For example, people may engage more frequently with a practice nurse, telephone coach or with peers, but less with hospital services. The aim is not to reduce contact overall, but rather to support a different pattern of contact which may lead to fewer crises and inpatient admissions.

What type of support works?

There are a wide range of initiatives to support self-management including information leaflets, online peer support, one to one counselling, group education sessions, telephone coaching, monitoring symptoms with technology, and psychological behaviour change interventions. Initiatives can be categorised along a continuum, with passive information provision about people's condition and 'technical skills' at one end of the scale and initiatives that more actively seek to support behaviour change and increase self-efficacy at the other end of the continuum.

All of the different types of support are important components of the jigsaw needed to encourage self-management, but information provision alone is unlikely to be sufficient to motivate behaviour change and improve outcomes.

Figure 1: continuum strategies to support self management



More active goal setting and behavioural change interventions are needed.

Different clinical conditions may require varying approaches to support self-management. For instance, because of the nature of conditions such as diabetes, there is a role for structured patient education focused on technical or clinical information about diet, exercise and medication. For conditions such as depression on the other hand, there may be fewer 'technical' changes that people can make so the focus is instead on cognitive and behavioural interventions. Such interventions may be equally valuable for people with diabetes and other conditions where the focus to date has been mainly on providing 'technical' information, but this remains an emerging field of knowledge.

What else do we need to know?

There is evidence that several general principles are important when supporting self-management. These include: involving people in decision making; developing care plans as a partnership between service users and professionals; setting goals and following up on the extent to which these are achieved over time; helping people manage the social, emotional and physical impacts of their conditions; motivating people to self-manage using targeted approaches and structured support; helping people to monitor their symptoms and know when to take appropriate action; promoting healthy lifestyles and educating people about their conditions and how to self-manage; and proactive follow up, including providing opportunities to share with and learn from other service users.

Knowledge about how to support behaviour change and put these principles into practice is still being developed. Research suggests that in order to change behaviour, people need to want to change. 'Stage of change' models have been found to be useful in developing successful programmes.

Another core component is supporting clinicians to work with people to improve their motivation to change. It is important to understand the skills that clinicians need to help people make changes. There may also be a need to fundamentally change the way patients and practitioners see their roles to create more of a partnership approach, but to date evidence about this is limited.

To conclude, research suggests that supporting self-management works, and can have a real impact on how people think, feel and act. The challenge is to explore the best ways to support self-management and to help service users, clinicians and managers make this a reality.

Chapter 1

What is self-management support?

Health services in Britain are facing an enormous challenge. The population is growing in size and age and people are more likely to suffer from long term illnesses that require ongoing care.[44] There is a need to change the way systems work and this includes helping people to help themselves.

Long term conditions are leading causes of death and disability worldwide.[45] In Britain, the Department of Health estimates that 17.5 million adults may be living with one or more long term conditions.[46] At least 60% of adults report having one long term condition and this figure continues to grow due to an aging population and escalating risk factors such as obesity.[47]

Medical advances mean that people with illnesses such as heart disease and stroke now receive treatments that enable them to live longer and to enjoy a higher quality of life than would previously have been possible, but this also brings challenges. Health and social care services provide help when symptoms worsen, but most of the time people and their families are responsible for making decisions and influencing their own wellbeing. In the UK, about 80% of GP consultations, 60% of days spent in hospital and two thirds of emergency admissions are related to long term conditions,[48] but more than 80% of the care for people with long term illnesses is undertaken by the patient themselves or their carers.[49] This is known as self-management.

The Department of Health defines self-management as:

> *The actions individuals and carers take for themselves, their children, their families and others to stay fit and maintain good physical and mental health; meet social and psychological needs; prevent illness or accidents; care for minor ailments and long term conditions; and maintain health and wellbeing after an acute illness or discharge from hospital.* [50]

Supporting self-management means providing information and encouragement to help people maintain greater control by understanding their condition and being able to monitor and take appropriate action. Interventions to support self-management can be used at different points of the health continuum, from those who do not have a long term condition through to those who are living with severe and multiple long term conditions.

Health and social care services can support people to self-manage their conditions by encouraging engagement in decision making, educating people about their condition and care, motivating people to adopt healthy behaviours and helping them know when and how to seek help from professionals.[51]

Over the past decade there has been an increasing focus in the UK and around the world on supporting self-management. Many strategies have been tested, with varying success, including providing accessible information; communication skills training for service users and professionals; self-management skills training facilitated by lay people; nurse led telephone support; self-monitoring of clinical symptoms; and even text messages, computer forums and video games. This rapid review compiles evidence about the effects of supporting self-management on people's quality of life, clinical outcomes and health service use.

The review methods are summarised at the end of this document in appendix 1. In brief, two reviewers searched more than 10 bibliographic databases for research evidence published up until September 2010. More than 100,000 reports were scanned and the findings from over 550 high quality studies are included in the review.

The review does not aim to be exhaustive but instead provides a rapid and easy to use compilation of up to date evidence. First, we explore whether supporting self-management improves outcomes, then we examine the most effective types of support and areas in need of further development.

Chapter 2

Impacts of self-management

Evidence suggests that supporting self-management works. Supporting people to look after themselves can improve their motivation, the extent to which they eat well and exercise, their symptoms and clinical outcomes and can even change how they use health services.

Interventions to encourage and support self-management vary considerably in their aims, approach, content, delivery, duration and target group.[52] Therefore it would be misleading to refer to 'self-management initiatives' as an integrated whole. This section describes evidence about the impact of supporting self-management on people's attitudes, behaviours and outcomes, but it is important to emphasise from the outset that these results vary according to the type of support provided. The next section explores differences between various approaches.

2.1 Impact on self-efficacy

How people think and feel about their condition can have a big impact on their health behaviours and outcomes.[53–57]

> *Self-efficacy refers to an individual's belief in their capacity to successfully learn and perform a specific behaviour. A strong sense of self-efficacy leads to a feeling of control, and willingness to take on and persist with new and difficult tasks. When applied to health, this theory suggests that patients are empowered and motivated to manage their health problems when they feel confident in their ability to achieve this goal.*[58]

There is evidence that improved self-efficacy is correlated with improved health behaviours and clinical outcomes so it is valid to examine the impact of self-management support on self-efficacy as representative of other outcomes.[59–71]

A literature review found that involving people in ongoing health decision making and self-management can increase patient and family responsibility for the delivery of care, and help people adapt care regimens to their own lifestyles.[72]

However, the best strategies to encourage self-efficacy remain uncertain. A trial in the US examined the impact of empowerment and motivation on self-management behaviours. Those who felt more empowered and active were most likely to self-manage effectively. However specific self-management education programmes did not seem to make people more activated. The authors concluded that more research is needed to examine the best ways to support self-management in order to increase empowerment and motivation.[73] Others suggest that it is important to understand why people wish to receive self-management support in order to target assistance to their needs.[74]

A number of self-management interventions focus on confidence building and providing service users with the knowledge and skills to set personal goals and develop effective strategies for achieving them.[75–84]

For instance, UK studies suggest that people with arthritis taking part in self-management programmes feel more confident in their ability to manage and control their symptoms, feel less anxious about their disease, and may visit the doctor less frequently.[85–88] Similar studies are available for people with heart disease, lung disease, diabetes, asthma, stroke and many other conditions.[89–94]

Some suggest that supporting self-management can help people move through stages of change (transtheoretical model), becoming more motivated to alter their behaviours and sustain this long term.[95–99] Others have found that the effectiveness of self-management support varies depending on people's stage of change.[100–111]

Examples of targeting self-efficacy

A small randomised trial in Taiwan investigated the effectiveness of an empowerment programme in 50 people with end stage renal disease. The programme included identifying problem areas for self-management, exploring emotions associated with these problems, developing a set of goals and strategies to overcome problems and achieve goals, creating and implementing behavioural change plans and stress management. There were improvements in empowerment, self-care, self-efficacy and depression.[112]

Similarly, a trial in China examined layperson led self-management education for 954 people with hypertension, heart disease, chronic lung disease, arthritis, stroke, or diabetes.[113] There were improvements in self-care behaviour, self-efficacy, and health status, and reduced hospitalisations six months after the course. Integrating the delivery model into community organisations and working with service users as lay educators were key success factors.

2.2 Impact on self-care behaviour

There is evidence that self-management support can improve people's knowledge about their condition and care, how they feel about their condition, and their ability to cope day to day. It also develops self-management behaviours.[114–124]

For instance, a meta analysis of 82 studies found that self-management education improved knowledge, self-care behaviour, and metabolic control in adults with diabetes.[125]

Another review of randomised trials found that self-management education increases participants' self-efficacy, knowledge, symptom management, use of self-management behaviours and aspects of health status. The effects for children, young adults, and carers remain uncertain.[126]

Research has explored the perceived barriers and facilitators for lifestyle modification. For example a qualitative study with people with chronic obstructive pulmonary disease (COPD) found that the most successful self-management support requires a multifaceted approach incorporating strategies to show people how to change their behaviour. This and other studies suggest that self-management support that includes behaviour change strategies and problem solving skills is more likely to lead to improved self-efficacy and lifestyle modification.[130–133]

Programmes which combine multiple support strategies often work best. A randomised trial in New Zealand used interventions including a diary for recording daily weights and goals, attendance at a specialist clinic, and three self-management education sessions for people with heart failure. After one year, those taking part in the trial were more likely to have better self-management knowledge and behaviours compared to the usual care group. Patients who did not adopt self-management strategies had a greater chance of death or readmission to hospital.[134]

However, other studies have found no difference between self-management support and usual care regarding self-efficacy, behaviours and awareness.[135] Most of the studies that found no benefits were small scale, sometimes non-randomised, and often focused on less structured forms of self-management support. Thus, while the reported outcomes for self-management support vary, this may be due to research methods rather than inherent to self-management support itself.

Examples of impact on behaviour

Most of the available research focuses on the impact of group education sessions. For example, a five year randomised trial with more than 1,000 people in the UK found that self-management courses were associated with improved healthy behaviours, coping, communication with physicians and self reported health status, and fewer days in hospital.[127]

A comparison of routinely collected data for 15,190 older people with diabetes found that those who had attended self-management education were more likely to self monitor blood glucose levels, take appropriate medications and go for regular eye examinations.[128]

Benefits from other types of support have also been documented. For instance, researchers in the US found that sending weekly educational newsletters improved self-management behaviours among African Americans with diabetes.[129]

2.3 Impact on quality of life

Research suggests that supporting self-management can improve quality of life.[136–142] A number of studies have found a link between self-management education, self-care behaviours and psychological outcomes, stress, coping or quality of life.[143–151]

There is evidence that supporting self-management results in both improved confidence to self-manage and improved quality of life[152–155] and that self-efficacy or perceived control is correlated with improved quality of life.[156–158]

Examples of interlinkages

There is a close relationship between self-management attitudes, behaviours and quality of life. For instance, trials in China found that self-management education was associated with improved self-care behaviours which in turn were associated with improvements in quality of life, clinical outcomes and healthcare resource use.[159–160]

Another randomised trial in the US assessed a self-management programme for older people with deteriorating eyesight. The programme focused on enhancing problem solving skills and resulted in improved mood and reduced emotional distress, which in turn was associated with increased self-efficacy. Functional status and quality of life also improved, especially for those who were initially depressed. This suggests a link between active self-management education, self-management behaviours and quality of life.[161]

Similarly, a randomised trial in the UK found that a self-management planning intervention was associated with improved self-care for people with angina, including better diet and more exercise. The programme was also associated with improved anxiety and quality of life.[162]

There are some conflicting findings. A Cochrane review found that self-management education by lay educators may lead to short term improvements in self-efficacy, self rated health status and self-care behaviours but no improvements in quality of life.[163]

Likewise, a randomised trial with 131 people with asthma in Switzerland found that self-management education helped to improve self-management skills, self-efficacy and people's knowledge of their condition and care. However there was no improvement in quality of life or health outcomes.[164]

Another small trial in the UK found that supporting self-management improved self-efficacy and self-care in people with stroke but did not improve quality of life.[165]

Studies that have not found any effect tend to be small or to use less proactive strategies to support self-management, such as written information or short education sessions focusing on providing technical information.

2.4 Impact on clinical outcomes

Overall, the evidence suggests that there is likely to be a relationship between supporting self-management and clinical outcomes.[166–175]

Some studies suggest direct relationships between supporting self-management and improved clinical outcomes.[176–183] Other studies show a correlation, but not necessarily a causal relationship.[184–189]

Various types of self-management support have been found to improve physical symptoms or clinical outcomes in people with arthritis, asthma, diabetes, hypertension, heart disease, heart failure, stroke, cancer and other conditions, at least in the short term.[190–196]

For instance, a systematic review collated 71 trials of self-management education for people with long term conditions. The reviewers found that people with diabetes participating in self-management education had improved glycaemic control and blood pressure. People with asthma experienced fewer attacks after self-management education. Arthritis self-management education programmes had no significant effects. The authors concluded that self-management education programmes may have small to moderate effects for people with selected long term conditions. They noted, however, that study methods varied widely and were not optimal.[197]

Studies have also assessed interventions involving the family members of people with long term conditions.[206] For instance a randomised study of children with diabetes found that a family teamwork intervention prevented deterioration in glycaemic control.[207]

There are exceptions to these positive trends.[208] Some studies suggest no improvements in clinical outcomes. For instance, a randomised trial in London evaluated a card and letter encouraging people to prepare questions to ask at a hospital consultation. Half of those sent a card said they got more out of their consultation as a result, but there were no significant differences in outcomes.[209] Another randomised trial with 131 people with asthma found that improved self-management skills and self-efficacy did not result in health improvements.[210]

Others suggest that any improvements are short lived. A systematic review of 31 studies found that self-management education for people with diabetes improves clinical outcomes in the short term. The longer the self-management intervention, the longer the effect tends to last. Any benefits tend to decrease 1–3 months after the intervention ceases, suggesting that learned behaviours change over time.[211]

As with other outcomes, the level of engagement and activity may be an important success factor for improving clinical outcomes. A randomised trial in Argentina compared self-management education aimed at improving communication skills and empowerment versus a compliance based relationship between patients and professionals. The study found that the self-management approach was associated with improved clinical outcomes; in this case increased blood pressure control.[212]

The research methods used may be one of the reasons for differences in findings between studies. A systematic review found that while there were small improvements in mortality and healthcare resource use from self-management education, most studies were small and suffered from biases or methodological design flaws.[213] Thus, whilst overall findings about supporting self-management generally suggest positive impacts on clinical outcomes, the varied quality of research in this area emphasises that ongoing evaluations of self-management interventions are needed to continue to build the evidence base.

Examples of clinical improvements

A meta analysis assessed the effectiveness of self-management education in children and adolescents with asthma. The reviewers included 32 randomised trials with 3,706 children aged between two and 18 years. Self-management education was associated with improved lung function and self-efficacy and reduced absenteeism from school, days of restricted activity, and visits to A&E. Programmes based on peak flow monitoring, targeted interventions, and interventions with children with severe asthma had the most effect on clinical outcomes.[198]

Similarly, a cohort study in the US examined the relationship between self-management education, self-management behaviours and clinical outcomes for 428 people with diabetes. Education was associated with improved self-care and more controlled blood glucose.[199] People in the early stages or with less severe illness were more likely to benefit, and this finding has been replicated for other conditions.[200–201]

Another study in the US found that active self-management education was associated with improved empowerment and engagement between people with diabetes and clinicians. This resulted in improved glycaemic control.[202]

A review of self-management education in arthritis found reductions in pain and fatigue, improved activity levels, aerobic capacity and exercise endurance, reduced levels of disability and functional limitations, and improved self-reported health status.[203] Numerous similar studies are available about measures of pain and quality of life.[204–205]

2.5 Impact on health service use

There is evidence from the UK and elsewhere that self-management support can alter the pattern of healthcare service use and subsequent healthcare costs, though the evidence is more varied than for clinical outcomes.[214–223]

It has been suggested that self-management support programmes may reduce visits to health services by up to 80%.[224–229]

Numerous trials are available suggesting a link between self-management education and reduced or altered patterns of health service use.[247–252] But we need to be cautious when interpreting the findings because some research suggests correlations rather than direct links. Many studies have found that supporting self-management improves self-care knowledge or behaviours and reduces hospitalisations but they have not proven that self-care causes reduced resource use.[253–257]

The mechanism by which outcomes change remains uncertain. A randomised trial in the US for people with chronic depression and post traumatic stress disorder found that self-management support led to reduced healthcare resource use without any significant change in self-management behaviours.[258] Similar findings are apparent in research about asthma.[259]

Other evidence suggests limited impacts on service use or costs.[260–264] A systematic review of nine trials of self-management education versus usual care for people with chronic obstructive pulmonary disease found that self-management education reduced the need for rescue medication and increased courses of oral steroids and antibiotics for respiratory symptoms, but had no effect on hospital admissions, emergency department visits, days lost from work, or lung function.[265]

Similarly, an evaluation of self-management courses run in the UK by volunteer tutors at Depression Alliance, Diabetes UK, National Endometriosis Society, Haemophilia Society, British Liver Trust, ME Association, Action for ME, National Osteoporosis Society, British Polio Fellowship, Breakthrough Deaf Integration, and the LINK centre for Deafened People found small improvements in self-efficacy, but no significant impacts on the use of health services. The evaluators suggested that disease specific information may need to be included within the generic course structure.[266]

A randomised trial found that sending reminders about GP visits improved primary care visits and reduced emergency department visits in 174 children with asthma in Australia.[270] However another trial in the US found that teaching nurses about self-management as well as providing patient education did not affect hospitalisations.[271] This demonstrates that the link between supporting self-management and outcomes is complex and does not necessarily follow a linear pattern.

It also shows that most of the available evidence focuses on self-management education courses rather than the wider range of support initiatives available.

However, assuming that supporting self-management will reduce healthcare resource use is somewhat simplistic. The aim of supporting self-management may be to alter the pattern of behaviour and service use rather than reducing service use itself. Therefore it may be more useful to focus on whether different types of services are being used (such as primary care versus secondary care or telephone and online resources versus in person resources).

Overall however, despite some conflicting findings, the evidence suggests that proactively supporting self-management and focusing on self-efficacy and behaviour change can have an impact on clinical outcomes, crises and unplanned admissions or other costly emergency service use.

Examples of impact on resources

Benefits may remain over the long term[230–231] and have been found throughout the world.[232]

Evidence about health service use tends to focus on complex mixed method approaches to support self-management, or group education courses.

The following randomised trial in the UK can be used as an example of a mixed method approach. In the trail 203 people with ulcerative colitis who were undergoing hospital follow up were either given patient centred self-management training and follow up on request, or usual care and routine follow up. Self-management training was associated with faster access to treatment when needed, reduced hospital visits (0.9 versus 2.9 per patient per year), and fewer GP visits (0.3 versus 0.9 per patient per year).[233–234] A success factor was giving service users the control to access care when they felt they needed it.

Another randomised trial in 19 hospitals in northwest England examined whether a whole systems approach to self-management was cost effective among 700 people. Consultants were trained to provide a patient centred approach to care and patient guidebooks were developed in partnership with service users. All patients prepared written self-management plans. After one year, the self-management group had fewer hospital visits and patients felt more able to cope with their condition. Cost effectiveness analyses favoured self-management over usual care.[235]

Trials and descriptive studies in the UK suggest that group education sessions such as the Expert Patient Programme have the potential to reduce hospital admissions and days spent in hospital.[236–237] However evaluations to date have been uncertain about the impact on healthcare resource use.[238]

A survey with 1000 people who had attended an Expert Patient Programme in England found that people reported improved self-management, reduced medication use and fewer unscheduled visits to the GP and A&E,[239] but administrative data were not available to confirm this.

Evidence is available about similar types of self-management courses from around the world. A literature review found that structured Self-management education programmes improve self-care behaviours and can reduce healthcare resource use and expenditure. Potential benefits include fewer A&E visits, fewer hospitalisations, and reduced days spent in hospital.240 Even in low income settings, or where resources are poor, supporting self-management has been found to be useful.241

A meta analysis found that self-management education programmes improved knowledge of diabetes and clinical outcomes and reduced medication use. The authors concluded that for every five people attending a group based education programme, one person would be expected to reduce diabetes medication and this would impact on overall costs.[242]

Another example is a randomised trial in seven hospitals in Canada, which evaluated self-management education among people with moderate to severe chronic obstructive pulmonary disease hospitalised within the past year.

The programme involved weekly visits by health professionals over two months, with monthly telephone follow up. Self-management education was associated with 40% fewer hospital visits for chronic obstructive pulmonary disease and 57% fewer hospital admissions for other problems. Emergency department visits reduced by 41% and unscheduled physician visits by 60%.[243]

Similarly, a trial in the US assessed seven weekly sessions of peer facilitated self-management education, each of 2.5 hours duration, provided in community settings with groups of 15 to 20 participants. The programme reduced emergency department and outpatient visits, improved health behaviours, reduced symptoms, and improved health status. Reductions in service use and emotional distress were evident two years after the programme.[244]

Another randomised controlled trial in Norway assessed self-management education for people with asthma. The intervention included two education sessions plus two follow ups by nurses or physiotherapists.

At one year follow up those taking part in self-management education had reduced visits to GPs, reduced overall costs and improved quality of life.[245]

A randomised trial with children with asthma examined self-management education using interactive multimedia tools. The initiative was associated with increased asthma knowledge among children and caregivers, decreased asthma symptom days, fewer emergency department visits, and lower average daily doses of inhaled corticosteroids. Increased asthma self-management knowledge and behaviours were associated with fewer urgent physician visits and less frequent use of quick relief medicines.[246]

Examples of contradictory findings

A number of studies have found that supporting self-management has little or no effect on the use or costs of healthcare resources. For instance, a UK cost effectiveness analysis with more than 800 people with arthritis found that a six session self-management education programme may not save costs overall or be any more effective than usual care or providing written information alone.[267]

Another randomised trial in the UK found that a self-management cd rom for children with asthma improved self-management, self-efficacy and feelings of control but there were no significant reductions in crisis medication use or days off school.[268]

A Cochrane review found that education by lay educators may lead to short term improvements in self-management attitudes and behaviours but no improvements in healthcare resource use.[269]

Chapter 3

What works to support self-management

3.1 Self-management support approaches

A multitude of approaches have been tested to support self-management. These range from more passive information sharing approaches at one end of the spectrum to more active behavioural change interventions at the other. Another way to conceptualise self-management support is to divide interventions into those that focus on building knowledge and technical skills (such as insulin management) versus those that aim to build self-efficacy (confidence in self-care). Figure 1 illustrates these typologies and positions various types of self-management support along the continuum.

It is difficult to categorise interventions in this way because there is wide variation. For instance, one type of group education may focus solely on information provision whereas another group education programme may seek to build confidence and change behaviours.

While the placement of each individual intervention is illustrative only, and a matter for debate, conceptualising support approaches as a continuum is useful. Evidence from hundreds of studies suggests that the proactive interventions located in the top right hand quadrant of figure 1 may be associated with greater change or more sustained levels of behavioural and clinical benefits. This section provides a summary of key evidence about what works to support self-management.

3.2 Providing information

Providing information about people's condition and how to manage it is an important component of supporting self-management. Information can be provided using leaflets, websites, email, text messages, electronic forums, by telephone and in person individually or in groups.

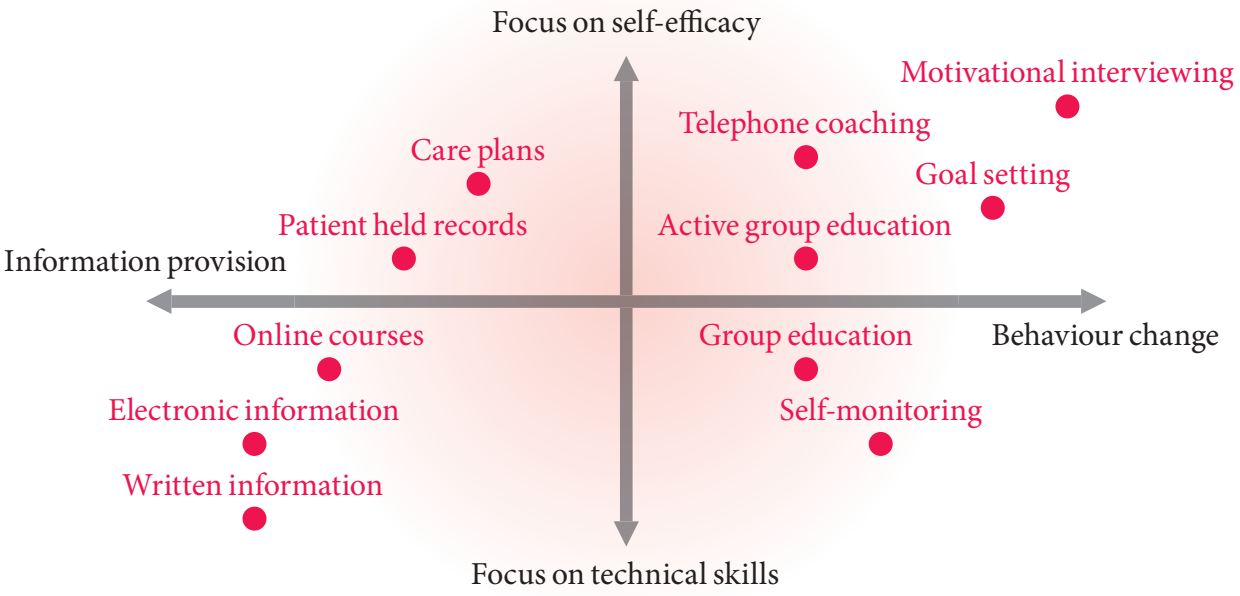
A great deal has been written about different ways to provide information to people with health conditions. We identified more than 60 systematic reviews and randomised trials about providing accessible information through written materials, educational sessions, and technologies such as the internet and video.

Researchers have examined the value of different approaches for supporting people with long term conditions generally as well as subgroups such as children and young people, older people and those from minority ethnic groups and deprived neighbourhoods.

Written information

A number of written information materials to support self-management have been evaluated, including guidebooks and printed educational materials.[272] There is some evidence that written motivational leaflets or letters can help people feel more confident to raise their concerns and discuss their symptoms,[273] but there is sparse evidence that such methods improve self-management behaviours or clinical outcomes.[274–275]

Figure 1: continuum strategies to support self-management



Other reviews suggest that printed materials can improve knowledge,[276–278] but may not impact behaviour when used alone.[279–280]

But findings are mixed. Some trials suggest that postal educational materials are as effective for improving symptoms and self-efficacy as group education sessions.[281] There is also evidence that combining written information with lectures or other educational activities can be more effective than written information alone.[282–283]

To understand these differences, it is worth considering the characteristics of the most effective written information tools. There is some evidence that targeting and personalising written information is more effective than standardised printed materials.[284–287] For example, a randomised trial in Scotland compared posting four personalised asthma education booklets versus conventional oral education at outpatient or surgery visits. Personalised booklets improved self-management and reduced hospital admissions.[288] Other studies have reinforced these findings.[289]

Electronic information sources

Self-management support can also be delivered using audiovisual technology, computers and the mass media.[291–294]

There is evidence that providing structured education programmes by video/dvd, audio or computer may be as effective as in person education groups.[295–296] For instance, a randomised trial with older people with long term conditions compared group education, a home study intervention using videotapes and booklets, and a control group. Compared with controls, both educational interventions were associated with reduced pain, sleep difficulties, and symptoms of depression and anxiety. The video course was also associated with reduced symptoms. The authors concluded that lower cost, more accessible home study education using video or dvd may be an effective alternative to group instruction for people with long term conditions.[297] Other research has similar findings.[298]

Other novel approaches have been tried. A randomised trial in the US tested an asthma education video game as part of a self-management programme for high risk children with asthma. The video game was associated with improved quality of life and asthma knowledge.[299]

Researchers in many parts of the world have tested using computers to provide self-management information and education.[300–310] For instance, a systematic review of 22 randomised trials found that computerised patient education improved health status in people with various conditions.[311] Studies also suggest some benefits for children and young people[312–313] and less advantaged socio-economic and ethnic groups.[314]

However while there are some positive trends, other studies have found limited or mixed benefits from online information and support programmes.[315–317]

A number of computer based peer to peer communities and electronic groups have been set up to support self-management but their effects remain uncertain.[318] Some descriptive studies suggest that computer chat rooms, coaching and other online forums can provide a good motivator for self-care,[319–321] but the effect on clinical outcomes is uncertain.

Another novel approach is using text messages or pager messages as reminders and support mechanisms.[322–323] One trial found that, when combined with other strategies, sending text messages to young people with diabetes helped to improve self-management behaviours.[324]

One randomised trial assessed sending standardised health promotion email messages to people weekly for 12 weeks. People who received emails had better self-management behaviours and reported favourable changes in healthy eating and physical activity.[325] Other studies suggest that email interventions can be targeted to the person's 'stage of change', thus providing more tailored and meaningful support.[326]

To summarise, evidence suggests that providing information in writing or electronically can improve people's knowledge about their condition and care. This may or may not translate into feeling more confident about looking after themselves and improved self-management behaviours.[327–328]

Systematic reviews, randomised trials and other high quality research has found that when used alone, information provision can improve some health behaviours but this does not tend to have lasting follow on effects on clinical outcomes or health service use. However, when used as part of a broader support initiative, information provision has been found to be useful, especially if it is targeted or personalised to account for people's individual needs.[329]

Example of tailored information

A systematic review of 60 randomised control trials examined the effectiveness of self help interventions for smoking cessation. The review found that the personalised written materials were more effective than individualised advice from a clinician, which was in turn more effective than non-personalised written materials. Adding additional face-to-face or other advice to tailored written materials did not improve effectiveness compared to personalised materials alone.[290]

3.3 Providing support

Another type of self-management support involves helping people to change their attitudes, perhaps through care planning, patient held records, decision support tools or other support mechanisms. This is different from information provision alone because the interventions aim to provide incentives for change or help people learn new skills or practical strategies for coping.

Decision support tools

For example, decision support tools have been used to support self-management.[330] Such tools may encourage service users and their carers to take more responsibility for their care, help people with long term conditions feel more in control, encourage health professionals to follow recommended care protocols, and have some impacts on quality of life.[331–332] But reviews about written decision aids suggest that such aids generally affect attitudes and knowledge rather than behaviours.[333–334]

Patient held records

A number of strategies have been trialled to increase people's involvement in healthcare processes and decision making as a way of facilitating self-management. Sometimes people are given their medical records to keep and bring to each consultation, which is known as patient held records.

A number of reviews and trials suggest that patient held records have limited effects on self-management. For instance, a trial of patient held records for people who had suffered stroke in the US found that while participants were pleased to have a copy of their records, took them when they visited doctors, and reported learning more about their stroke, there was no difference in health practices or behaviours compared to usual care.[335] Randomised trials in the UK have drawn similar conclusions about patient held records.[336–337]

There is also interest in making records available electronically for service users.[338–340] A randomised trial in the US provided patient records online to people with heart failure. After one year, those who had access to their records online were more likely to adhere to treatment, but there were no differences in self-efficacy or satisfaction with care.[341] This suggests that patient held records may have some impacts on self-management strategies, but these impacts are not clear cut. The evidence is too mixed to suggest that patient held records are a useful enabler for self-management.

Planning and agenda setting

A care plan is a written document collaboratively designed by service users and professionals covering issues, interventions and review processes.[342]

Care plans may include both goal setting and developing plans for how to achieve these goals.[343] Most of the available evidence about self-management treatment plans focuses on people with asthma or COPD, though there is emerging evidence about other conditions.[344]

There is evidence that action plans or proactive planning support may improve self-management behaviours for people with long term conditions,[345–354] and this may impact on healthcare resource use.[355–357]

Numerous examples are available. For instance, systematic reviews support an agenda setting action plan coupled with self adjustment of medications and regular medical review for people with asthma.[358–359]

A randomised trial of 140 adults with asthma or chronic obstructive pulmonary disease assessed developing a written self-management plan in groups coupled with individual educational sessions. The plans were associated with improved medication compliance among people with asthma, but not chronic obstructive pulmonary disease.[360]

In New Zealand, a randomised trial found similar benefits from written self-management plans for children with asthma.[361]

However, there are questions about whether agenda setting and care planning are supported by practitioners and service users[362] or directly impact on clinical outcomes.[363] A Cochrane review with seven randomised trials examined whether a written asthma self-management plan increased adherence to medications and improved clinical outcomes. There was no strong evidence that written plans improved patient outcomes. One type of agenda setting was not consistently more effective than another.[364]

Another review found that adding written self treatment guidelines to self-management programmes may improve health outcomes, but the only two controlled studies on this topic found no effect.[365]

A randomised trial in France found that when agenda setting and plans were used as part of a self-management programme, only those who adhered fully to the self-management plan had improved symptoms.[366]

Evidence about the impact on healthcare resource use is mixed.[367] A Cochrane review of 36 randomised trials of asthma self-management programmes found that combining self-monitoring and written agenda setting reduced hospitalisations, emergency department visits, unscheduled visits to the doctor and days off work or school. The reviewers concluded that programmes that enable people to adjust their medication using a written action plan are more effective than other forms of asthma self-management.[368]

Stepwise agenda setting and planning has also been found to be beneficial for people with COPD. A randomised trial in Norway found that GP visits reduced by 85% and there was less need for medication and reduced overall health costs during a 12 month follow up period.[369] Other forms of agenda setting and care planning have also been found to have an impact on healthcare resource use.[370]

However other reviews and trials have found limited benefits from agenda setting and care planning,[371–372] particularly for those who have been hospitalised.[373–375]

Studies have attempted to explore why action plans and agenda setting seem to work well sometimes and not other times, but few firm conclusions are possible. Plans and agenda setting seem to be better when care plans are provided and supported in primary care compared to secondary care. This approach may be better as a 'preventive' measure rather for those with the most severe disease, or for those who are hospitalised for the first time.[376]

Goal setting and follow up

Self-management education often includes some form of goal setting.[377–380] A number of studies have outlined the benefits of goal setting as part of self-management support.[381–391]

For instance, a trial in the US found that personalised goal setting as part of a self-management support intervention for older women with heart conditions was associated with reduced days in hospital and reduced overall healthcare costs.[392]

Research has examined the benefits of following up service users to support them in achieving goals and improving self-management behaviours.[393–398] For example, a review of workplace self-management interventions found that offering opportunities to practise skills and have ongoing follow up were key success factors.[399]

A small randomised trial found that self-management counselling with goal follow up improved the use of community resources, physical activity and adherence to medication.[400] Other trials have found improved self-care knowledge and behaviours[401–402] and reduced hospital admissions and days in hospital when proactive follow up is used as part of self-management support.[403]

Another trial in the US assessed the cost effectiveness of a brief dietary intervention for people with diabetes. The intervention included touch screen computer assisted assessment, goal setting, follow-up calls, and videotape intervention at regular intervals. The intervention was low cost and improved self-care behaviour significantly.[404]

A trial in the Netherlands examined an electronic diary and follow up device based on the principles of motivational interviewing. When people took part in healthy behaviours, they were positively reinforced by the device. This type of follow up resulted in improved self-management.[405]

Not all findings about goal setting are positive. As part of a skill orientated self-management programme in the Netherlands, people with COPD recorded their symptoms in diaries and graded their health status from 1–10 in a weekly report. They used these documents to help them set and monitor goals. A randomised trial found no effect on quality of life or functional status.[406]

The thing that seems to make a difference is regular and proactive follow up. In the US, a randomised trial found that the more follow ups and support sessions involved, the more likely people were to control their diabetes.[407] However, another US trial tested whether telephone follow up every month or every three months following self-management education might be most effective. There were no significant differences between these follow up intervals on any clinical or quality of life outcomes.[408] This demonstrates that there is still a lot to learn about the best strategies for supporting self-management.

Behaviour change approaches

The most promising way of supporting self-management appears to involve approaches which empower and activate people so they feel more confident about managing their conditions and are more likely to alter their behaviours. There is strong evidence suggesting that improved self-efficacy is associated with better clinical outcomes.[409–411]

These approaches include motivational interviewing by telephone or in person, group or individual education programmes with an active component, coaching with proactive goal setting and follow up, and programmes based on psychological and emotional support that acknowledge people's stage of change.

Individual and group education sessions are the most commonly evaluated interventions of this type, though there is also an increasing focus on telephone coaching by nurses.

Example of stage of change approach

Researchers in the US tested assessing people's capabilities for self-management and then tailoring telephone coaching support based on this assessment. Compared to usual disease management, the group receiving tailored support based on their 'stage of change' felt more empowered, had improved clinical outcomes and reduced their use of health services.[412]

Individual education sessions

A number of studies have assessed the impacts of one to one self-management support sessions for people with long term conditions.[413–414] For instance, a randomised trial in the UK assessed whether specialist asthma nurses could increase knowledge and improve self-management during one to one sessions in hospital. People receiving individual education had increased knowledge and less emergency GP call outs in the four months after hospital discharge. Hospital readmission rates were similar between groups.[415]

Generally, studies suggest that while individual education may increase people's knowledge, it is unlikely to have significant impacts on behaviour and clinical outcomes unless it is targeted, specific, and long term.[416]

Individualised coaching may be especially beneficial when combined with personalised written materials or other mechanisms to support self-management.[417] For example, a large meta analysis of interventions for people with high blood pressure assessed individual education, self blood pressure monitoring, and structured courses. Individual education was the most effective single strategy for improving blood pressure control, but combining individual education and group sessions was even more effective.[418] Other reviews have found similarly positive results for people with heart failure,[419] arthritis,[420] diabetes,[421] and asthma.[422]

There has also been success when using individual person centred discussions initially, followed by referral to other self-management support strategies (such as educational groups) once needs have been established.[423]

Though most individualised counselling has been trialled with nurses or family doctors, pharmacists are increasingly being acknowledged as a valuable resource in supporting self-management.[424]

Group education courses

A great deal has been written about self-management group education programmes, including those adapted to specific cultures, demographic groups, learning styles or disease types.[425–440]

Group education and peer support programmes aim to help people learn how to manage their own care more effectively, including when to use different healthcare services and resources.[441–442] More than 60 systematic reviews and numerous additional randomised trials are available in this area.[443–444] Most take place in health settings or the community, but workplace and family support programmes and school education have also been trialled.[445–447,]

Research generally suggests that group education can improve people's self confidence, clinical outcomes and even health service use. However, not all programmes have been successful, especially with regard to improving symptoms or reducing healthcare use.[448–456]

Reviews and meta analyses are less likely than individual trials to demonstrate a difference but this may be because reviews tend to combine many different interventions and may evaluate interventions using different outcomes than they were set up to achieve.[457–458]

Education sessions range from those focused on 'technical' information such as how to monitor blood pressure and what foods to eat, to more 'proactive' courses which seek to change people's attitudes towards self-management and motivate behaviour change. There is evidence that courses which focus on enhancing self-efficacy or combine technical education with more proactive motivation have most effect on clinical outcomes.

Telephone coaching

Various types of telephone based support and coaching have been tested to encourage self-management.[459–462]

A number of studies suggest that proactive nurse led telephone calls can be used to encourage self-monitoring and self-management.[463–467] For example, a randomised trial with 'high risk' people with diabetes found that automated educational calls with telephone follow up by nurses may improve self-care behaviour, glycaemic control, and symptoms among vulnerable people.[468] Similar evidence is available from many parts of the world.[469]

A study in the US found that motivational interviewing helped improve self-efficacy, patient activation, lifestyle change and perceived health status.[470] There are many similar studies about the benefits of motivational interviewing, some of which combine both face to face and telephone approaches.[471]

There is also evidence about the benefits of more detailed case management via telephone.[472] A randomised trial in the US evaluated six months of standardised telephone case management for 358 people with heart failure. Telephone case management helped to motivate people to self-care, and was associated with about half as many hospitalisations for heart failure, fewer days in hospital, and lower inpatient costs after six months.[473]

There is evidence to suggest that telephone support is often just as effective as face to face supported self-management.[474–475]

But not all studies are positive. For instance a trial with more than 300 people with diabetes, predominantly from minority ethnic groups, found that clinic based telephonic disease management support in between primary care visits did not improve clinical or behavioural outcomes at one year compared to people receiving usual care.[476] Feedback from service providers also suggests there can be practical and technical difficulties.[477]

Work based support

Work based programmes are gaining increasing recognition for supporting self-management, especially in the US where health insurance is often part of employment packages. One of the key differences between workplace programmes and those run by governments or health services is that programmes in the workplace can specifically target a 'captive audience' and may be able to focus on people at higher risk more easily.[478]

A number of group education and individualised counselling approaches have been tried, whereby employees are followed up regularly in the workplace.[479–483] Other workplace initiatives include distributing written materials,[484] providing health risk assessment,[485] health fairs, weight loss and nutrition classes, fitness programmes, social networks,[486] online support[487] and environmental changes such as introducing walking tracks around the work environment.[488]

While there is little evidence about the most effective workplace strategy, most research suggests that these initiatives can help to support self-management behaviours. One review of 35 different interventions found that offering people the opportunity to practise skills and have ongoing follow up was more effective than education alone.[489]

Another review found that providing individualised risk reduction programmes for high risk employees is a critical element of successful worksite interventions.[490] This emphasises that regardless of the setting, proactive interventions appear more effective for encouraging self-management behaviours and resulting changes in clinical outcomes.

Self-monitoring and telemonitoring

Self-monitoring involves service users monitoring their symptoms in order to track their progress, modify their behaviours or medications accordingly, or assess when to seek help from health professionals.[491] Self-monitoring is often linked with electronic monitoring devices, but this term can also refer to written management plans and systems to help patients self refer to health services.[492] We identified more than 50 studies about self-monitoring, most of which had positive outcomes, though not all were of high quality.[493–499]

Randomised trials suggest that electronic self-monitoring may have some clinical benefits.[500–502] For instance, a trial in Germany found that a self-monitoring blood glucose device for people with diabetes improved glycaemic control and general wellbeing.[503] Other trials support the value of self-monitoring for people with diabetes,[504–506] asthma,[507–509] and high blood pressure[510–511] amongst others.[512–514]

However, there are some conflicting findings.[515] A trial in Scotland concluded that prescribing peak flow meters and giving self-management guidelines to everyone with asthma is unlikely to improve mortality or morbidity.[516] Another UK trial found that self-monitoring did not improve self-management or symptoms in children with asthma.[517] It appears that those most likely to benefit from self-monitoring have the most severe disease.

Although there is evidence that self-monitoring can have some impact on clinical outcomes, there is limited evidence about the effect on use of resources.[518] Self-monitoring may also be inappropriate or unfeasible for some.

A Cochrane review found that compared to standard monitoring, people who self monitor can improve the quality of their oral anticoagulation therapy and resulting clinical outcomes.

However, self-monitoring or self-management were not feasible for up to half of the people requiring anticoagulant therapy due to patient refusal, exclusion by their GP, or inability to completetraining.[519]

Schemes which use telecommunications systems such as the internet or telephone lines to transfer or record monitoring information are often referred to as 'telemonitoring'. This is not always strictly 'self-monitoring' as it may involve interaction between service users and health professionals,[520–521] but it is another way to support self-management.

There is mixed evidence about the value of telemonitoring,[522] but it is well received by patients and providers.[523–524] Most high quality information about the effect of telemonitoring on clinical outcomes focuses on people with diabetes or hypertension, although studies with other patient groups are emerging.[525] Most available evidence suggests that transmitting data about diabetic symptoms or blood pressure via telephone lines can improve self-management and have a positive effect on clinical outcomes.[526–531] This is especially true when the system is liked to nurses or doctors who review the information and provide feedback to patients or take action when needed.

To summarise, the evidence suggests that not all mechanisms to support self-management have equal outcomes. Whilst information provision and building technical skills is important, this is just one aspect of self-management support. Approaches which recognise people's motivations and needs, take account of their level of desire to change (or stage of change) and support people emotionally and psychologically have been found to have more sustainable impacts on behaviour, clinical outcomes and healthcare resource use.

Furthermore, there is an increasing focus on supporting self-care in a way that involves people's carers and family members.

Evidence to date tends to focus on children, young people and older people, but there is scope for more detailed examination of engaging families to support self-care for a wider range of people.[532–533]

Chapter 4

Issues that need more attention

4.1 Changing behaviours

The evidence is clear that supporting self-management can have real benefits for people using services and their families, and the wider health economy. However this is a relatively new area of investigation and knowledge continues to develop.

Interventions to support self-management vary considerably in their aims, approach, content, delivery, duration and target group. Even so, there are some general principles that have been found to work well to support self-management, including:

- Involving people in decision making; proactive education.
- Setting goals and following up on the degree to which these are achieved over time.
- Helping people manage the social, emotional and physical impacts of their conditions.[534]

While general principles are clear, the best strategies for motivating people to change their behaviours remain uncertain. Work has been done around smoking cessation, sports psychology and the stages of change model, all of which examines how to improve self-efficacy and motivation to change. How applicable this is to people with long term conditions in the UK is unknown.

A number of innovative strategies are being tested to support behaviour change in the UK, including the Health Foundation's Co-creating Health initiatives. Rigorous evaluation of these programmes and wide dissemination of learning will enhance knowledge in this area considerably.

4.2 Supporting clinicians

The attitudes and skills of healthcare providers can have a significant effect on the extent to which people feel engaged and supported and this is an area in need of further exploration.[535–542]

If people are to be more involved in decisions about their care and more active in keeping themselves well, clinicians need to be able to communicate information effectively and to consider what level of involvement is appropriate for different people.[543–544] There may still be considerable work to do in this area.[545–547] Interviews with GPs in 11 European countries found that most GPs thought that involving people in healthcare decisions had positive outcomes. But GPs defined patient involvement narrowly, thought it took place solely during consultations and felt that they had limited time to engage with people.[548] Thus there may be work to do to educate clinicians about the value and scope of supporting self-management and the skills they need to achieve this.

Research in the UK suggests that clinicians may take a 'compliance orientated' approach to self-management and this is unlikely to be helpful.[549]

A number of strategies have been tested to improve clinician communication strategies and help professionals support self-management.[550–557] For example, a randomised trial found that training GPs about risk communication tools and shared decision making for people with long term conditions could improve prescribing and was unlikely to have major impacts on the cost of care in the UK.[558] However, another UK study found that while GPs appear receptive to patient involvement, training in shared decision making and risk communication did not help them achieve this or improve patient outcomes.[559] This shows that knowledge is limited about the best strategies to help clinicians support self-management.

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Appendix 1

Review methods

To collate evidence, two reviewers searched bibliographic databases, reference lists of identified articles and reviews, and the websites of relevant agencies for information available as at September 2010. The search, analysis and narrative synthesis were completed over a three week period. The databases included:

- Medline
- Embase
- ERIC
- Science Citation Index
- Cochrane Database of Systematic Reviews
- Cochrane Controlled Trials Register
- DARE
- NHS Health Technology Assessment and Economic Assessment databases
- NHS Research Register
- NHS Evidence
- US National Electronic Library for Health
- PsychLit
- the WHO Library
- Agency for Healthcare Research and Quality
- Web of Knowledge
- Ovid.

All databases were searched from inception until present using terms such as self-management, self care, self-efficacy, self help, self treatment, self-monitoring, home monitoring, self medication, support, social support, peer support, mutual support, self-management education, long term conditions, chronic care, coping skills, behaviour change, care plans, patient held records, home care, telemedicine and telecare.

To be eligible for inclusion in the review, studies had to:

- be primary research or reviews
- be published research
- be readily available online, in print or from relevant organisations
- be available in abstract, journal article, or full report form.

Studies in any language were eligible. Randomised controlled trials and systematic reviews were prioritised, though less rigorous designs were also included if few randomised trials or systematic reviews were available.

We scanned more than 100,000 pieces of research, selecting the highest quality and most relevant to summarise here. No formal quality weighting was undertaken.

More than 550 of the highest quality studies and descriptive overviews were synthesised. Data were extracted from all publications using a structured template and studies were grouped according to topic areas and outcomes to provide a narrative summary of key trends. Meta analysis was not appropriate given the diversity of the material.

When interpreting the findings it is important to bear in mind several caveats. Firstly, interventions to support self-management vary considerably in their aims, approach, content, delivery, duration and target group.[560–562] Therefore it would be misleading to refer to 'self-management initiatives' as an integrated whole. In the main, this review does not differentiate between various types of interventions because the aim is to examine the effects of self-management support in all its facets. However, it should not be assumed that all types of self-management support have the same impacts or findings.

In most cases there is limited detail within research reports about how programmes are implemented. This means that it is difficult to differentiate the most effective components or strategies. Similarly, most available research does not assess the mechanisms by which supporting self-management may work. The focus tends to be on outcomes such as quality of life, functional status, clinical outcomes and healthcare resource use. The relationship between a specific self-management intervention and these outcomes is explored, but the mechanisms by which these outcomes may occur tend to receive less attention.

A lack of evidence or comparisons does not necessarily mean that there is no relationship or benefit, just that there is currently insufficient research to draw conclusions.

Finally, much of the available evidence is sourced from countries with very different healthcare economies and styles of working than the UK so may not be directly comparable.

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