Prioritising person-centred care

Supporting self-management

Summarising evidence from systematic reviews

National Voices
People shaping health and social care

Key themes

We compiled information from 228 systematic reviews and found that the top things you can do to support self-management are:

- providing self-management education for people with specific conditions which is integrated into routine healthcare
- generic self-management education courses co-led by peers / laypeople
- interactive online self-management programmes
- telephone support and telehealth initiatives
- self-monitoring of medication and symptoms

The table signposts to evidence about what works best to support self-management. Initiatives in bold have the most evidence to support them. As the quantity of literature is large, only selected examples of relevant studies are included in the table.

Focus	Improves knowledge	Improves experience	Improves service use and costs	Improves health outcomes
Targets patients	• **Group-based self-management education**[1,2,3] • Online education[4,5] • Mobile phone interventions[6,7] • Educational materials[8]	• Group-based self-management education[9,10]	• Disease-specific group education[11,12,13,14,15] such as **asthma self-management courses**[16,17,18,19,20] • Psychosocial interventions[21] • **Self-monitoring**[22,23,24]	• **Group-based self-management education**[25,26,27] • **Online education**[28,29,30] • **Telehealth**[31,32,33,34] • Video games[35] • Psychosocial interventions[36,37,38] • **Self-monitoring**[39,40,41,42,43,44,45]
Targets professionals		• Training professionals[46]		
Targets systems / organisations			• Simplified dosing strategies[47,48]	• Disease registries[49]

Supporting self-management

Person-centred care involves placing people at the forefront of their health and care. This ensures people retain control, helps them make informed decisions and supports a partnership between people, families and health and social services.

Some of the core components of person-centred care involve:

- supporting self-management
- supporting shared decision-making
- enhancing experience
- improving information and understanding
- and promoting prevention

We have a series of booklets for healthcare commissioners and professionals summarising the best research evidence about what works in each of these areas. This booklet focuses on supporting self-management.

What is self-management?

People can play a distinct role in protecting their own health, choosing appropriate treatments and managing long-term conditions. Self-management includes all the actions taken by people to recognise, treat and manage their own healthcare independently of or in partnership with the healthcare system. People feel more confident and engaged when they are encouraged to self-manage by professionals, therefore supporting self-management is key to prioritising person-centred care.

Why is this important?

1. A large number of people live with long-term conditions

More than 15 million people in the UK live with a long-term medical condition that cannot currently be cured. The number is set to rise by 23% over the next 25 years. Three out of every five people aged over 60 suffer from a long-term condition and about 85% of deaths are from long-term diseases.

People with long-term health needs may require personalised support to help manage their health and their use of health and social care resources. The Department of Health wants every person with a long-term condition to have a care plan and access to their health records; and wants care to be better coordinated around their needs.

2. Supporting self-management has the potential to reduce costs

People with long-term conditions use:

- 52% of all GP appointments
- 65% of all outpatient appointments
- 72% of all inpatient bed days

Nearly 70% of NHS spending on primary care and hospital care supports people with long-term conditions. The UK economy stands to lose roughly £16 billion over the next 10 years through premature deaths due to heart disease, stroke and diabetes.

Supporting people to take a more active role in managing their own conditions can reduce service usage. Most care for people with long-term conditions is provided at home by themselves, their partners, families and carers. If more people could do this successfully, without needing to receive urgent care or be admitted to hospital, the NHS would become more sustainable.

3. People with long-term conditions need different types of support

The care needs of people with long-term conditions are different from those of people experiencing emergencies. Top-down delivery to a passive patient is unlikely to work. People with long-term conditions need sufficient motivation, information, skills and confidence to make decisions about their health and to manage it effectively.

People with asthma need to know when to use their inhalers. People with diabetes need to monitor their blood sugar levels and people with arthritis need to learn how to cope with the pain and, where possible, how to ameliorate it. People with these and other long-term conditions also have to cope with the emotional impact of having an illness that cannot be cured, and with the practical effects on their daily lives.

4. People want more support to self-manage

Almost everyone wants to do all they can to maintain and improve their health, but they need advice and support to do so effectively. A MORI survey for the Department of Health found that:[50]

- 82% of people with a long-term condition said they already play an active role in their care but would like to do more,
- more than 90% were interested in being more active self-carers,
- more than 75% said that if they had guidance and support from a professional or peer they would feel far more confident about taking care of their own health.

The national NHS patient surveys carried out for the Care Quality Commission suggest that many people are not receiving sufficient support to enable them to look after themselves effectively. About four out of ten people say they are not given any written or printed information about what they should or should not do after leaving hospital and that staff do not tell them about medication side effects to watch for when they go home or danger signals they should watch for. A quarter of hospital inpatients were not told who to contact if they were worried about their condition or treatment after leaving hospital and the same proportion of people with long-term conditions said they did not receive sufficient support from local services to manage their own condition.

5. Policies and regulators mandate self-management support

The NHS Constitution for England says that people have the right to be involved in discussions and decisions about their healthcare and to be given information to enable them to do this.

The Health and Social Care Act requires all health and social care providers to, where appropriate, provide opportunities for service users to manage their own care or treatment; and provide appropriate opportunities, encouragement and support to service users in relation to promoting their autonomy, independence and community involvement.

The Care Quality Commission, which regulates the quality of health and social care on behalf of patients, service users, their carers and families, has issued guidance to providers on meeting the statutory requirements to enable people to have choice and control and to manage their own care.

The General Medical Council says doctors should support people in caring for themselves to improve and maintain their health. Good Medical Practice suggests: "This may include advising patients on the effects of their life choices on their health and well-being and the possible outcomes of their treatments."

The Nursing and Midwifery Council says nurses and midwives "must support people in caring for themselves to improve and maintain their health."

What works?

228 systematic reviews published between 1998 and 2013 have summarised the best research evidence about supporting self-management.

This section outlines key findings about what works to support self-management so commissioners and professionals know the most useful and cost-effective interventions to invest in.

The appendix describes how we identified and analysed the research evidence.

What has been tested?

Systematic reviews have explored research evidence about the following initiatives:

Self-management education

- Generic self-management education
- Self-management education for people with specific conditions such as arthritis/rheumatic disease, asthma, cancer, cardiovascular disease, chronic Obstructive Pulmonary Disease (COPD), diabetes, epilepsy, HIV/AIDS, hypertension, mental health issues and stroke
- One-to-one counselling or advice
- Cognitive behaviour therapy, motivational interviewing and stress management
- Exercise programmes
- Community support
- Printed information

Using technology

- Online education programmes
- Telephone support including helplines and text messages
- Video games
- Dvds

Self-monitoring

- Self-monitoring of medication or symptoms
- Simplified medication dosing strategies

Interventions for professionals

- Training in self-management support

What are the impacts?

Improving knowledge

There is strong evidence that self-management support helps to increase people's knowledge about their condition, how to self-care and when to appropriately use health services.[51,52,53,54,55,56,57,58,59,60,61,62,63,64,65,66,67,68;69,70,71,72,73,74,75,76,77,78,79,80,81,82,83,84,85,86,87,88,89,90,91]

Group education

Group-based self-management education has been found to improve knowledge about specific conditions and about self-care.[92,93,94] However improvements may only last short-term.[95]

Using technology

Online education and support has been found to improve knowledge in people with long-term conditions and mental health issues.[96,97] There is some evidence to support smartphone technologies, text messages and electronic memory aids.[98,99,100]

Educational materials

Educational materials such as booklets, leaflets and dvds have all been found to improve knowledge about people's condition and self-management.[101] However, used alone such materials may not motivate people to change their behaviour.

Improving experience

Most research suggests that self-management support can improve:[102,103,104,105,106,107,108,109,110,111,112,113,114,115,116,117,118,119,120,121,122,123,124,125,126,127,128,129,130, 131,132,133,134,135,136,137,138,139,140,141]

- people's satisfaction
- coping skills
- confidence to manage their condition (self-efficacy)
- perceptions of social support
- health literacy

However, most studies look at short-term outcomes rather than long-term effects.

Group education

Group self-management education has been found to improve linkage to, and possibly retention in, care as well as feelings of coping and self-efficacy.[142,143]

In children, education linked to practical activities, homework, sport or art has been found to work well.[144,145]

Interventions for professionals

Training health professionals using face-to-face lectures, assigned readings, mentorship and critiqued evaluations of consultations has been found to impact positively on the self-management support provided, and patient experience.[146]

Improving service use and costs

Group education

There is also evidence that supporting self-management can reduce the use of health services. There is conflicting evidence of an effect on service use as a result of generic lay-led self-management programmes.[147] **Disease-specific** programmes may be more effective.[148,149,150,151,152]

For example, reviews have found fewer hospital admissions, unscheduled visits to the doctor and days off work or school as a result of self-management education and care planning for people with asthma.[153,154,155,156,157,158,159,160,161] Self-management support may also reduce hospital admissions for people with COPD.[162,163,164]

There is some limited evidence of a reduction in hospital admissions following interventions to improve adherence to antipsychotic medication.[165,166] A review found that self-management education interventions for people with schizophrenia were associated with a significant reduction in relapses and re-hospitalisations. People who took part in self-management education were more likely to improve adherence to medication and have improved symptoms compared to people receiving usual care.[167]

Home-based self-management information and communication interventions for people with long-term conditions can reduce healthcare costs.[168]

Findings are mixed regarding cost-effectiveness. Most economic analyses find that diabetes self-management education is cost-effective.[169] On the other hand, a review of the cost-effectiveness of self-management support for older people with chronic pain had mixed findings. Many studies suggested no benefit compared to usual care, but others suggested that the cost of developing and delivering self-management interventions may be partly offset by savings from reduced subsequent use of health services.[170]

Other initiatives

There is evidence that **self-monitoring** of oral anticoagulation is as effective as specialist management and superior to GP care, but wide adoption could cost the NHS an additional £8-14 million per year.[171,172,173]

Simplified dosing strategies can help people take their medicines appropriately.[174,175]

Psychosocial interventions which focus on behavioural change and emotional support have been found to reduce costs associated with medication and healthcare use.[176]

Improving health behaviour and outcomes

The impact of supporting self-management on behaviour change and clinical outcomes is less clear.

Group education

Reviews have found small but statistically significant improvements following structured **group self-management education** across many health status measures including pain, disability, fatigue, depression, health distress, diet, physical activity, symptom management, self-rated health and health-related quality of life.[177,178,179]

For specific conditions there are some positive trends:

- Most reviews - but not all - found improvements in blood sugar control following self-management support for people with **diabetes**.[180,181,182,183,184,185,186,187,188,189,190,191,192,193,194,195,196,197,198,199,200,201,202,203,204,205,206] Self-management programmes can improve quality of life for people living with diabetes, and internet-based interventions can improve monitoring and attendance for diabetes-related health checks.[207,208] However, other reviews suggest that diabetes education alone is unlikely to improve metabolic control.[209]

- Self-management support improves adherence to treatment recommendations and can reduce seizure frequency among people with **epilepsy**.[210,211,212]

- Self-management support can improve treatment adherence, improve physical symptoms and reduce unsafe sex among people with **HIV/AIDs**.[213,214,215,216]

- Self-management support, health education and stress management programmes can improve health outcomes for people with **heart disease** and heart failure.[217,218,219]

- Self-help smoking cessation interventions and resources are more effective than usual care in helping women to stop smoking during **pregnancy**.[220]

- Other conditions where self-management education has been found to improve behavioural or clinical outcomes include arthritis, high blood pressure, lower back pain , irritable bowel syndrome and stroke.[221,222,223,224,225] For example, short-term improvements in health status have been found following arthritis self-management education, though these were not always sustained over the longer-term.[226,227,228,229]

Some reviews have less positive findings:

- Mixed results were found in health status outcomes following attendance at asthma self-management programmes.[230,231,232,233,234,235,236,237,238]

- Mixed results were seen regarding psychological outcomes following support programmes for people with cancer.[239,240,241,242,243,244,245,246] Fatigue-specific psychosocial interventions for people receiving cancer treatment may be effective in reducing fatigue.[247]

- There is little evidence of significant improvements in health status as a result of self-management support for patients with COPD, though there may be improvements in reported quality of life. Some reviews have found a trend towards improved health outcomes , so the findings are mixed.[248,249,250,251,252]

- Collaborative care and self-management support can improve treatment adherence and reduce depression,[253,254,255] but there is mixed evidence about clinical effects for people with mental health issues.[256,257,258,259,260,261,262,263,264,265,266,267,268,269,270,271]

- Other conditions where there is limited evidence for health status improvements following group education include psoriasis and lymphedema.[272,273]

- There is little evidence to suggest that interventions intended to improve medicines adherence and treatment outcomes for people with long-term conditions have been effective.[274,275]

Using technology

Online self-management support programmes have been found to improve diet, physical activity and symptom control. Success factors include having **interactive components** with data tracking and personalised feedback, behaviour change activities and providing opportunities for peer support.[276,277,278]

Online programmes have been associated with greater self-efficacy for managing long-term conditions. Reviews report that people benefit from communicating with health professionals or website moderators to receive feedback and social support. Asynchronous communication tools such as email and discussion boards as well as progress tracking features such as graphical displays of uploaded personal data were found to be particularly useful for motivating changes in behaviour.[279]

A review of IT to support self-management included studies about the internet, mobile phones, telemedicine, and electronic decision support techniques. Interventions where several technologies were integrated showed the most potential for improving self-management behaviours.[280]

Telehealth may include telephone helplines, proactive telephone support, mobile phone apps and consultations via telephone. There is some evidence that telephone support can improve self-management confidence and behaviours, and in some instances clinical outcomes.[281,282,283,284] For example, mobile phone technologies were found to improve blood sugar control in people with diabetes.[285] Telehealth has been found to have most impact on health change in people with long-term conditions who are most unwell or most at risk of hospital admissions.[286]

A review found that **video games** could be used to support physical therapy, psychological therapy, self-management and health education, as well as training for health professionals.[287]

Another review of interventions for young people using **electronic media** found improved outcomes such as increased fruit, juice, or vegetable consumption; increased physical activity; improved asthma self-management, and sexual abstinence.[288]

Technologies such as falls sensors and electronic medication reminders have been found to impact on wellbeing and outcomes for frail older people.[289]

On the other hand a review of text messages and email self-management support found no improvements in health outcomes.[290]

Psychosocial interventions

Psychosocial interventions involve targeting emotional and cognitive issues, rather than solely focusing on how to self-manage. They may include motivational interviewing, cognitive behavioural therapy, mindfulness and other proactive support.[291,292,293] They can be delivered in person or by telephone. Online initiatives are emerging but have less commonly been included in systematic reviews.

Some reviews suggest that psychosocial interventions can reduce anxiety, depression and stress in people with long-term conditions or mental health issues.[294,295,296] Brief counselling, monitoring and feedback has also been found to improve medication adherence.[297] Psychosocial interventions may also be effective in helping people with a coronary heart disease to stop smoking.[298]

Self-monitoring

Reviews have found that home blood pressure monitoring plus counselling, education and reminders can lead to better blood pressure control among people with hypertension.[299,300,301,302,303,304,305] Self-monitoring and remote monitoring may also improve quality of life in patients with cardiovascular disease.[306,307,308,309] Amongst people taking oral anticoagulation medication, self-monitoring has been found to reduce thromboembolic events,[310] particularly amongst those young than 55 years.[311] There is also some evidence that self-monitoring of medication may improve patient safety.[312]

Other initiatives

System-level initiatives that have been found useful in supporting diabetes self-management behaviours include disease registries, providing access to electronic medical records and training for professionals. Linking to community resources may also be useful.[313]

What should we invest in?

Taking all of the evidence together, commissioners and providers wanting to enhance experience could consider investing in the initiatives listed below.

Improvement initiatives	Expected return on investment
Self-management education and support for patients with specific conditions, integrated into routine care with active involvement of health professionals	Improved patient knowledge and understanding Improved confidence and coping ability Improved health behaviours *May* improve adherence to treatment recommendations *May* improve health outcomes *May* reduce hospital admission rates *May* be cost-effective
Lay-led generic self-management educational courses	Improved patient knowledge and understanding Improved confidence and coping ability Improved social support *May* improve health outcomes
Interactive online self-management programmes	Improved patient knowledge and understanding Improved social support Improved health outcomes Improved health behaviours
Proactive telephone support and psychosocial support	Improve confidence Improved self-management behaviours *May* improve adherence to treatment recommendations *May* improve health outcomes *May* be cost-effective
Home-based self-monitoring	*May* improve health outcomes *May* improve quality-of-life
Simplified dosing strategies and information	Improved adherence to treatment recommendations

There is good evidence that it is possible to improve people's knowledge and understanding of their condition, leading to greater confidence for self-management. Effective self-management can lead to improvements in health outcomes for certain conditions.[314,315] Long-term conditions are often associated with anxiety and depression, so supporting self-management also has the potential to improve mental wellbeing and overall quality of life.[316,317,318] There is some evidence that effective self-management support can lead to reduced hospital admission rates. Self-management support programmes take a wide variety of forms and may need to be tailored to people's demographic characteristics and the type of condition.[319,320] Involving family members may also be useful for sustainability.[321,322]

There have been a very large number of studies about this topic, but overall the top three things that might usefully be invested in are:

1. Disease-specific, generic and online self-management courses

The evidence suggests that disease-specific self-management education, with professional involvement provided as part of routine healthcare, is more effective than generic self-management educational courses led by lay people. On the other hand, lay-led self-management courses are popular with attendees. They strengthen social support and coping skills in the short-term, but there is no evidence of long-term effects. Interactive online self-management programmes can have a beneficial effect on behavioural and clinical outcomes.

There is no strong evidence about the best people to provide self-management support in order to improve health outcomes. Some reviews suggest that having health professionals involved is important,[323] but people with long-term conditions, nurses, doctors, pharmacists, community workers, allied health professionals and others have all delivered education to good effect.[324] Having facilitators specifically targeted to particular cultural and linguistic demographics has also been tested.[325]

A 'review of reviews' concluded that "educational programmes have definite benefits for patients suffering from asthma and are promising for interventions in areas such as diabetes mellitus, epilepsy and mental health. However, it still is not clear what the active ingredients of many successful interventions are."[326]

Self-management education can take place in the **community or in hospital**.[327] A review of education around the time of hospital discharge to support self-management found reduced reported anxiety and depression and increased subjective health, although some studies had mixed findings.[328]

'Standard' self-management education programmes are six to eight weeks long, with participants attending once per week for two or three hours. Longer courses have not been found to be more effective.[329]

In terms of content, **proactive problem solving**, cognitive behavioural therapy, behaviour change principles and practical or physical activities have been found to be useful.[330,331,332,333,334,335,336,337,338] Some reviews suggest that **disease-specific** programmes are more effective than generic self-management education, and that courses should be appropriately targeted for specific cultures and subgroups.[339,340]

Reviews have reported that useful elements in **online interventions** include education, self-monitoring, feedback and tailored information, self-management training, personal exercise programmes, and email or instant message communication with either health professionals or other patients.[341,342,343]

Some reviews suggest that self-management education alone is unlikely to improve clinical outcomes. Instead it needs to be part of multifaceted interventions that also target clinicians, the environment and **wider health systems** issues.[344,345,346,347,348]

2. Proactive telephone support

Health coaching, motivational interviewing and other psychosocial interventions delivered by telephone have been found to improve knowledge and self-care behaviours, and may have a follow-on effect on clinical outcomes when coupled with other proactive support. These interventions are often delivered by nurses.

3. Self-monitoring of symptoms and vital signs

Self-monitoring by patients can be effective for increasing self-care and reducing reliance on health service, but cost-effectiveness has not been proven.

Whatever type of intervention is implemented, it is important to measure impacts properly. A range of validated tools are available to measure the extent of self-management and associated outcomes.[349,350,351,352]

Learn more

You can access the abstracts of all the systematic reviews of evidence by clicking on the hyperlinks in the references section of this document.

There are a number of other resources available, such as:

- Self-management education courses have been designed to help people learn how to manage their condition and cope with the effects on their daily life. Some of these have been designed for people with specific conditions such as asthma, arthritis or diabetes. Others are generic education programmes for people with various forms of long-term conditions. Some courses are led by healthcare professionals; others by lay people with experience of long-term conditions. QISMET is an independent body that sets standards and certificates providers of self-management, patient education and self-care interventions.

- Self-management courses led by patients themselves were popularised in the US via the Chronic Disease Self-Management Programme. In England, the Expert Patient Programme, a community interest company, provides self-management courses for people with long-term conditions based on this model. They also train healthcare professionals in the skills needed to support people's self-management.

- The Department of Health has guidance on how to commission support for self-care.

- Year of Care aims to help healthcare professionals support and empower individual people to effectively self-manage their diabetes. The project is a partnership between Diabetes UK, the Department of Health, the Health Foundation and the National Diabetes Support Team.

- Funded by the Health Foundation, Co-creating Health involves an advanced development programme for clinicians, a self-management course for people with long-term conditions, and an organisational development programme. Demonstration sites around the country have worked with people with COPD, diabetes, depression and musculoskeletal pain.

- Surveys carried out as part of the Care Quality Commission's national NHS patient survey programme include a number of questions which can be used to monitor the extent to which patients are given adequate support for self-management. The Department of Health's General Practice Patient Survey also includes a set of questions examining whether the patient and the GP or nurse discussed the management of their condition.

Appendix: identifying evidence

Commissioners and professionals need accessible and accurate information upon which to make decisions. High quality research is one of the things that might be used to help guide decisions. This appendix describes how we compiled the highest quality research to support decision-making.

What type of evidence is included?

To find out what works best to prioritise person-centred care, we drew on systematic reviews. 'Systematic reviews' have traditionally been regarded as the best standard of evidence because they bring together the results of all relevant studies that meet specific quality criteria. A systematic review starts with a specific question or set of clearly defined questions and then identifies, appraises, selects and synthesises all high quality research evidence relevant to that question. Tried and tested methods are used to perform a thorough search of the literature and critical appraisal of individual studies to identify valid and applicable evidence.

Some groups, such as the Cochrane Collaboration have agreed a set of standards for gathering, analysing and reporting evidence, though not all reviews conform to these standards.

By drawing together the findings of systematic reviews, we compiled the highest quality evidence to support healthcare planners and practitioners. We focused on the extent to which interventions impacted on people's knowledge, people's experience, service use and costs and health outcomes and behaviours.

Identifying research

Two reviewers independently searched bibliographic databases to identify relevant systematic reviews and other high level narrative reviews. The databases were Medline / Pubmed, Embase, CINAHL, the Cochrane Library and Google Scholar. Specialist websites and the reference lists of identified articles were also searched. The databases were searched for systematic reviews published in English language journals between January 1998 and December 2013.

Reviews were eligible for inclusion if they focused on interventions designed to enhance the active role of patients and lay people. Reviews where patients were solely the 'objects' of an intervention that targeted professionals were excluded. Two reviewers independently assessed the relevance and quality of each review, first based on the abstracts and titles of identified studies and then based on full-text. Any review which focused on a relevant topic and outcome was included.

More than 40,000 studies were screened and a total of 779 systematic reviews were identified for inclusion, broken down into the following categories:

- supporting self-management (228 reviews)
- supporting shared decision-making (48 reviews)
- enhancing experience (110 reviews)
- improving information and understanding (85 reviews)
- and promoting prevention (308 reviews)

Things to remember when interpreting the findings

The evidence base is substantial and significant, but it is not perfect. It will not help to answer all questions about how best to prioritise person-centred care. Some interventions, such as education for self-management, have been very well studied. Others initiatives have been less well investigated, and few studies have examined the longer-term effects of interventions.

Much of the research is from North America, so commissioners and health professionals need to think about whether the findings translate easily to the local context.

Although there is good evidence that some things make a difference to how people feel and what people do, analysis of cost-effectiveness is sometimes lacking.

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Exploring the evidence

You can click on the hyperlinks to explore the evidence further.

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