

Supported self-management for respiratory conditions in primary care

FAQs and evidence

Stephanie JC Taylor Centre for Primary Care and Public Health, Barts and The London School of Medicine and Dentistry, Queen Mary University of London, UK and **Hilary Pinnock** Asthma UK Centre for Applied Research, Usher Institute of Population Health Sciences and Informatics, The University of Edinburgh, Edinburgh, UK

Over the past two decades Governments and health services across the world have developed an intense interest in promoting better self-management or self-care, particularly amongst people with long-term conditions, as a way of improving population health and containing spiralling health care costs.¹⁻³ Health care professionals have, understandably, sometimes been less enthusiastic about supporting self-management and have questioned the importance of, and their role in, this endeavour.

In 2014 we published a major, overarching review (the PRISMS study) that looked at the research evidence around self-management support for 14 diverse long term conditions, including asthma and COPD.⁴ Based on this work, much of which we have since updated, and on other published research, this article addresses some of the common concerns we have encountered when discussing self-management support with colleagues in primary (and secondary) care.

1. What is "self-management" anyway?

The terms self-management and self-care are often used interchangeably but it can be helpful to distinguish between them. Self-management refers to *"those actions individuals and others take to mitigate the effects of a long term condition and to maintain the best possible quality of life"*. Self-care refers to "a wider set of behaviours which both the healthy and the not so healthy take to prevent the onset of illness or disability, and, again to maintain quality of life".⁵

Self-management involves all the aspects of a person's life that may be affected by living with a long term condition and "... is defined as the tasks that individuals must undertake to live with one or more chronic conditions. These tasks include having the confidence to deal with medical management, role management and emotional management of their conditions."⁶ Living with a long term condition inevitably involves an individual taking decisions about (or 'self-managing') their condition for better or worse - even entirely ignoring a long term condition is a way of self-managing for some people. Health care professionals, and others, can support individ-

uals in their self-management, helping them to manage their conditions as effectively as possible to maintain health and wellbeing, so we talk about "supported self-management".

Based on our PRISMS study⁴ we developed a classification, or taxonomy, which encompasses possible different activities which might be used to support self-management.⁷ These fourteen potential support interventions for self-management, together with examples of activities for asthma and COPD taken from national guidelines, are shown in Table 1.

It is important to note that not all these interventions are necessarily effective, appropriate or even evaluated in every long term condition, and no self-management intervention we are aware of encompasses everything on this list. This is a pick-list, not a check-list.

2. Do patients really want to self-manage, can all patients self-manage, isn't it just trying to get health care on the cheap?

To understand what patients have said about their experience of self-management, and what they would like to support them, the PRISMS study included an overarching review of the published reviews and syntheses of qualitative research around the 14 long term conditions.⁴ In addition to studies of self-management support, we included reviews looking at the experience of living with long term conditions in order to extract anything that might be relevant to self-management support.

From 30 reviews including 515 unique qualitative studies we identified several common themes. Almost every study highlighted *a need for health care professionals to provide patients with information about their condition and the desire by patients for good collaborative relationships with their health care professionals - we suggest that these two aspects are the cornerstones of self-management support*. The importance of information from health care professionals was also reported in an overview of self-management support by National Voices.⁸

Table 1. Components of the PRISMS taxonomy of self-management support with examples from asthma and COPD

Potential interventions for self-management support from the PRISMS Taxonomy	How this might apply to asthma <i>(Examples of recommendations taken from British guideline in the management of asthma²² except*)</i>	How this might apply to COPD <i>(Examples of recommendations taken from NICE Guidance on COPD[†] 2010³² except*)</i>
1. Providing people with information about their condition and/or its management	"Education is a core component of effective self-management programmes in adults and children"	"Specific educational packages should be developed for patients with COPD."
2. Providing people with information about relevant available resources (such as financial benefits, local support groups and charities)	Provide information about Asthma UK (www.asthma.org.uk) *	"Patients disabled by COPD should be considered for referral for assessment by a social services department."
3. Provision of/agreement on specific clinical action plans (which may include rescue medication)	"All people with asthma (and/or their parents or carers) should be offered self-management education which should include a written personalised asthma action plan and be supported by regular professional review."	"The impact of exacerbations should be minimised by: giving self-management advice on responding promptly to the symptoms of an exacerbation..." ⁿ
4. Regular clinical review by a health care professional	"In primary care, people with asthma should be reviewed regularly by a nurse or doctor with appropriate training in asthma management. Review should incorporate a written action plan."	"Patients with COPD should be reviewed at least once per year, or more frequently if indicated..."
5. Monitoring of the long term condition, by the patients themselves or others, with feedback to the patient	"In adults, written personalised asthma action plans may be based on symptoms and/or peak flows: symptom-based plans are generally preferable for children."	"In older patients attention should also be paid to changes in weight, particularly if the change is more than 3 kg."
6. Practical support with adherence (medication or behavioural)	"Adherence to long-term asthma treatment should be routinely and regularly addressed by all healthcare professionals within the context of a comprehensive programme of accessible proactive asthma care."	"Unless contraindicated, offer nicotine replacement therapy, varenicline or bupropion, as appropriate, to people who are planning to stop smoking combined with an appropriate support programme to optimise smoking quit rates."
7. Provision of equipment to enable, assist or promote self-monitoring and/or self-management of the LTC	"Children and adults with mild and moderate asthma attacks should be treated with a pMDI + spacer with doses titrated according to clinical response."	"People who are already on long-term oxygen therapy who wish to continue with oxygen therapy outside the home, and who are prepared to use it, should have ambulatory oxygen prescribed."
8. Provision of easy access to advice or support when needed	"Strategies that have been used in effective [supported self management] interventions include... telephone calls to provide ongoing support and advice."	"For most patients with stable severe disease regular hospital review is not necessary, but there should be locally agreed mechanisms to allow rapid access to hospital assessment when necessary."
9. Training/rehearsal to communicate with health care professionals	Not specifically mentioned in either guideline but strategies which have been suggested may help include the patient writing a list of questions before eth consultation and the patient making an audio-recording of the consultation to listen to again later.*	
10. Training/rehearsal for everyday activities	"Immediately prior to exercise, inhaled short-acting β_2 agonists are the drug of choice"	"Pulmonary rehabilitation should be made available to all appropriate people with COPD, including those who have had a recent hospitalisation for an acute exacerbation."
11. Training/rehearsal for practical self-management, for example training in use of an inhaler	"Before initiating a new drug therapy practitioners, should check adherence with existing therapies, check inhaler technique, and eliminate trigger factors."	"Patients should have their ability to use an inhaler device regularly assessed by a competent healthcare professional and, if necessary, should be re-taught the correct technique."
12. Training/rehearsal for psychological strategies	"In difficult childhood asthma, there may be a role for family therapy as an adjunct to pharmacotherapy"	"Healthcare professionals should be alert to the presence of depression in patients with COPD. The presence of anxiety and depression should be considered in patients: who are hypoxic who have severe dyspnoea who have been seen at or admitted to a hospital with an exacerbation of COPD."
13. Social support	"Peer-led interventions for adolescents in the school setting should be considered."	Patients should be made aware of their Local Breathe Easy Groups.*
14. Lifestyle advice and support	"Parents with asthma should be advised about the dangers, to themselves and to their children with asthma, of smoking, and be offered appropriate support to stop smoking."	"Encouraging patients with COPD to stop smoking is one of the most important components of their management. All COPD patients still smoking, regardless of age, should be encouraged to stop, and offered help to do so, at every opportunity."

[†] Currently being updated

Other common issues important to patients highlighted in our PRISMS study were:

- The individuality of the illness experience for each patient
- Striking a balance between support and autonomy in relationships with carers
- The need for social and emotional support and/or helpful peer support
- The importance of psychological support
- The challenge of adherence to medication or treatment regimes.

From this it seems clear that patients do want support to manage their long term conditions. This qualitative research is backed up by a survey for the Department of Health by MORI in 2005⁹ which found that 87% of those surveyed who lived with a long-term health condition were 'interested' in playing a greater role in taking care of their condition (and nearly half were 'very interested').

Health care professionals may be concerned that not all patients are "capable" of self-management. In reality, however, all people with long term conditions are already taking decisions about their condition – regardless of their "capability". Patient's knowledge, confidence and ability to self-manage their health has been described as patient "activation"¹⁰, and the concept recognises that not everybody is at the same point when it comes to self-management. Patient activation can be assessed using a questionnaire (the Patient Activation Measure PAM 13)¹¹ and scores may be used to stratify patients from the lowest levels, where individuals may feel overwhelmed by managing their own health, through to the highest levels where individuals have adopted the behaviours they need to manage their conditions.¹² Being older, depressed or anxious, having poor health literacy, multimorbidity, and low social support tend to be associated with lower patient activation as does increasing COPD severity.^{13,14} There is some evidence that higher patient activation levels are associated with reduced hospitalisation and emergency room attendance but study designs have tended to be weak and there is very little evidence available on patient activation and outcomes amongst respiratory patients.¹⁵

Our own PRISMS work suggests that self-management support needs tailoring to the individual patient and their condition⁴, but we believe that all patients will benefit from considering how to support their self-management better. Some health care professionals, and indeed *some patients and carers, may be concerned that supporting self-management means abandoning patients to look after themselves*. This is categorically not the case, supporting self-management should be seen as an inherent part of good medical care - it does not replace the need for routine clinical reviews, access to professional advice, appropriate medication or other necessary clinical care – but it may well make this care more effective.

3. Does supporting self-management really work?

There is extensive evidence that interventions supporting self-management improve patient outcomes in a wide range of long term

conditions,^{4,8} In COPD, self-management interventions improve quality of life, reduce dyspnoea and reduce respiratory related and all cause hospital admissions,¹⁶ although it is not possible to identify the individual components or intervention characteristics which are most effective,¹⁷ nor which patients are most likely to benefit.¹⁸ It has long been known that asthma self-management that includes education about the condition, regular reviews and provision of a personalised asthma action plan reduces asthma hospitalisations, the need for unscheduled care, the use of rescue medications and days off work or school, whilst improving quality of life.¹⁹ The findings of 270 randomised controlled trials confirm that supportive self-management for asthma can be delivered effectively in a broad range of clinical settings across a wide range of different demographic and cultural groups without increasing total healthcare costs.²⁰

Moreover, evidence from our systematic review of 19 implementation studies demonstrated that it is possible to deliver effective supported self-management in routine clinical practice.²¹ We concluded that self-management support interventions which operated at the level of the patient, the health care providers and the health care organisation had the most consistent evidence of benefit in clinical and process outcomes.

4. "It's not my job, the nurse does it....."

As described above, structured education reinforced with ownership of a personalised asthma action plan is an example of effective, evidence based asthma self-management support and is a key recommendation in the British Guideline on the Management of Asthma.²² In fact this was recommended in the original British Thoracic Society asthma management guidelines in 1990.²³ Personal action plans are a visible marker of supported self-management, despite this asthma action plan ownership remains low with surveys from the UK, United States, Europe, and Australia reporting that less than a third of people with asthma have an action plan.²⁴⁻²⁸ In 2014 the UK National review of Asthma Deaths (NRAD) found fewer than one quarter of those who died had had a personal asthma action plan.²⁹

Pulmonary rehabilitation (PR) is a very well evidenced intervention supporting self-management in COPD³⁰ and is recommended in guidelines.^{31,32} The UK National COPD Pulmonary Rehabilitation Audit has drawn attention to the relatively low proportion of people referred to PR who actually complete the programme (42%)³³ but cannot measure the proportion of patients with COPD eligible for PR who were not referred in the first place. Anecdotally this is believed to be high with huge variations in referral rates between individual general practices. Surveys in a range of countries, including the UK, report physician referral to PR of between 2 and 16% of potentially eligible patients.³⁴

Why is the implementation of these heavily evidence based self-management support interventions so poor? One of the problems is likely to be seeing self-management support as someone else's role rather than a shared activity to which everyone in the health

care team contributes. The current model of UK primary care where including supported self-management is typically seen as the role of the practice nurse or a respiratory nurse specialist within chronic disease care, whereas unscheduled care for exacerbations is often provided by a general practitioner or NHS out of hours services. Whilst this may represent a practical delegation of tasks, it risks causing a division in roles which may undermine doctors' confidence and skills in discussing self-management, and can leave the nurse feeling unsupported. As a result supported self-management may slip down the list of practice priorities.³⁵ Awareness of different roles enables members of the team to reinforce tasks and 'sell' effective interventions to patients. For example, we know that the enthusiasm of the referring doctor is a factor associated with uptake of the offer of PR.³⁶

Green, researching in a single, integrated care organisation in the States, compared characteristics of physicians and other health care professionals whose patients tended to become more activated over time with those whose patients had not.³⁷ Features of health care professionals whose patients' activation increased included:

- Spending time on patient education
- Emphasising that patients owned their condition
- Working in partnership with patients on goal setting and problem solving
- Helping to break problems down into small steps
- Scheduling more frequent follow ups
- Telling patients how much they valued them.

In contrast, those whose patients tended not to become more activated spent time telling patients the negative health outcomes they could expect if they did not change their behaviour and reported spending little time on lifestyle issues. Interestingly in both groups most of the professionals interviewed had not been trained in supporting behaviour change and had developed their skills through trial and error.

5. It all sounds great but there isn't enough time to do it...

UK primary care feels hard pressed and in the current environment health care professionals may feel they simply don't have enough time to support self-management. However, the time commitment is balanced by a reduction in unscheduled care (in asthma) and admissions (in COPD).^{16,20} Moreover, we argue that developing self-management skills is a process not an event,³⁸ so that whilst initial time may be delegated to an asthma review, we can all provide on-going support at every opportunity – often in only a few seconds (see Box for some very practical examples from the latest BTS/SIGN guideline.²²) Finally, in addition to benefiting patients, supporting self-management may lead to more satisfying practice for the clinician; for example, an approach to a review that starts with the patient's agenda, and sees supporting people to understand and cope with their condition as a core objective (and as QOF is reduced in importance) reduces the primacy of tick boxes.

Box: Practical activities to support self-management in asthma reproduced from the BTS/SIGN Asthma Guidelines.²²

- A hospital admission represents a window of opportunity to review self-management skills. No patient should leave hospital without a written personalised asthma action plan.
- An acute consultation offers the opportunity to determine what action the patient has already taken to deal with the asthma attack. Their self-management strategy may be reinforced or refined and the need for consolidation at a routine follow up considered.
- A consultation for an upper respiratory tract infection or other known trigger is an opportunity to rehearse with the patient their self-management in the event of their asthma deteriorating.
- Education should include personalised discussion of issues such as trigger avoidance and achieving a smoke-free environment to support people and their families living with asthma.
- Brief simple education linked to patient goals is most likely to be acceptable to patients.

A report by The Health Foundation³⁹ identifies seven features to help embed self-management support:

1. Building a shared vision
2. Creating a strong infrastructure for implementation, but...
3. Fostering local innovation and ownership
4. Harnessing peer power
5. Starting small and scaling up over time
6. Remembering the importance of evidence at all stages
7. Considering sustainability from early on.

Conclusions

All people living with a long term condition are self-managing and the vast majority want support from trusted health care professionals to understand and manage their condition better. Supporting self-management is entirely compatible with the patient centred, holistic nature of primary care and in essence represents good medical care. Supporting self-management is not the sole responsibility of patients, carers or a single group of health care professional but a shared activity which should be everyone's responsibility. Nor does it mean abandoning patients to look after themselves, indeed

regular medical review is a key component of self-management support for patients with asthma and COPD. Health care professionals will need training to optimise their skills, but *embedding self-management support for asthma and COPD in our routine care should result in better outcomes for patients*, reduced unscheduled health care use, and more satisfying practice for clinicians.

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