Improving care for COPD: Implementing NICE Quality Standard 10, Statement 2

(People with COPD have a current individualised comprehensive management plan, which includes high-quality information and educational material about the condition and its management, relevant to the stage of disease.)

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BetterKnowledgeBetterCare
1 Introduction

A literature review was carried out to identify, reference and summarise the current evidence base regarding the delivery of effective interventions relating to Chronic Obstructive Pulmonary Disease (COPD) care in the NICE Quality Standard 10 Statement 2:

People with COPD have a current individualised comprehensive management plan, which includes high-quality information and educational material about the condition and its management, relevant to the stage of disease.

This report presents the findings of the review, focusing on the following key elements:

- The gap between current and ‘best’ practice;
- Addressing barriers to implementation. (Barriers include obstacles preventing the patient from participating and factors affecting the professionals’ ability to implement something);
- The potential impact on patient outcomes;
- Cost effectiveness;
- Emerging recommendations for the NHS.

In the interest of brevity, the search strategies/histories and complete findings are not included in this report but can be requested from NEQOS.

Much research has focused on pulmonary rehabilitation\(^1\) (which is also separately addressed in the Quality Standard.) The separate elements of self-management, exercise and education have also been studied in depth. Because of the significant overlap between the elements and the way programmes are delivered to patients, this report includes some results relating to pulmonary rehabilitation in general and some relating to exercise and education as well as those specifying ‘self-management’.

This report is one of a series of four NEQOS reports, covering a range of the Quality Statements in NICE Quality Standard 10. (The other three consider the following aspects: medication in primary care, non-invasive ventilation in hospital and appropriate palliative care.)

\(^{1}\) Pulmonary rehabilitation is a package consisting of self-management, exercise and education.
2 The gap between current and best practice: what is the gap?

An NHS Companion Document sets out how the NHS can deliver against the Outcomes Strategy for COPD and Asthma. The *NHS COPD Commissioning Toolkit: A resource for commissioners*, states that the Companion Document has:

- set out the key areas for improving the quality of care for people with COPD, including using quality-assured spirometry and assessment, providing pulmonary rehabilitation, carrying out home oxygen assessment and review, and managing exacerbations.

There is strong evidence that these interventions help to reduce mortality, improve quality of life and recovery, improve patient experience and improve patient safety – so are relevant to all five domains of the NHS Outcomes Framework.

We know from the National COPD Audit and other research that the provision, quality and take-up of these services is variable across England.

National and European COPD Audits and World Health Organization data show, among other things, that, as well as the UK’s death rates being higher than European average death rates:

- Less than a third of England’s COPD sufferers have been diagnosed.
- Some areas of England see four times as many emergency admissions due to COPD than other areas.
- If the whole NHS were to deliver services in line with the best, around 7,500 lives could be saved each year.

A 2012 European COPD audit\(^1\) expressed concerns over suboptimal treatment of the disease. It referred to the findings of several studies suggesting that over 90% of eligible patients did not join a pulmonary rehabilitation programme. Another 2012 audit (BTS)\(^2\) found that although stopping smoking is the most cost-effective treatment for COPD, fewer than 30% of the third of COPD sufferers who smoke had been referred for smoking cessation. However, the BTS Audit also found that the majority of patients were now offered Pulmonary Rehabilitation.

Despite overwhelming evidence, self-management support is still not being implemented into routine clinical practice\(^3\).
3 Delivering effective actions to reduce the gap

3.1 Self-management and education

Mastering effective breathing and sputum clearance techniques are essential for patients with COPD and, as Bourbeau suggests, ‘rather than telling the patient to learn to live with their disease, they should be taught to self-manage’. Planned inhaler training has been found to decrease attack frequency and dyspnoea and improve quality of life. The ‘teach-back’ technique, used as an educational intervention for teaching COPD patients to use a respiratory inhaler, has been shown to increase significantly the proportion of patients using inhalers correctly. Brief nurse-led interventions can significantly increase self-care adherence to medication. Japan has been successfully using a network of certified community pharmacists to deliver correct inhalation techniques, significantly reducing the frequency of exacerbations and increasing medication adherence. Brief nurse-led interventions can lead to a reduction in respiratory problems.

A lay and clinician-led COPD self-management programme has the potential to produce improvements in important outcomes such as activation, mastery and self-management abilities. Both patient knowledge and clinical indicators can improve and the patient can feel empowered. From the English GP patient survey, it is known that ‘doctor communication most influences people’s overall level of satisfaction with general practice’, helping to reduce stress and to make patients feel enabled. Linked with good communication is good two-way communication, as there is evidence that patients want more involvement in making decisions about their care, so that doctors need to listen as well as talk.

Many patients wish to be supported to self-manage. Successful interventions in supporting self-management include: health promotion; health coaching/counselling; education activities; use of smartphone apps for behaviour change; improving health literacy. The evidence is as yet not conclusive for the use of computerised clinical decision support systems for chronic disease management but one study found that a small majority (just over half) of such systems improved care processes in chronic disease management and some improved patient health.

Although one 2006 study found that self-management plans made no difference to quality of life or health outcomes, the inclusion of action plans within some self-management programmes have been found to be successful in reducing hospitalisations. A Cochrane review found that there was evidence that action plans with limited COPD education aid recognition of, and response to, an exacerbation with initiation of antibiotics and corticosteroids. However, it found no evidence of reduced healthcare utilisation or improved quality of life and went on to say that ‘the practice of giving patients an action
plan and limited self-management education for the management of COPD exacerbations, without a multi-faceted self-management program or ongoing case management cannot be recommended as the standard of care in COPD.

### 3.2 Encouraging exercise and lifestyle change (including stopping smoking)

Both exercise and self-management are advocated in pulmonary rehabilitation for people with COPD\(^1\). Self-management programmes that address behaviour can increase self-reported exercise even when exercise is not a programme component\(^1\), \(^2\).

Four years after one nurse-led self-management programme\(^2\), participants had maintained their exercise capacity and two out of three participants had continued to exercise regularly.

Moderate exercise using a virtual game system (e.g. Wii or Nintendo) has been found to be safe, feasible and enjoyed as an adjunct to inpatient pulmonary rehabilitation and might encourage patients to maintain physical activity after pulmonary rehabilitation\(^2\).

Structured programmes with self-care education have been found to be effective in motivating patients to change lifestyles\(^3\), which might include both exercise uptake and smoking cessation. Encouraging patients with COPD to stop smoking is one of the most important components of their management and all COPD patients, regardless of age, should be encouraged to stop, and offered help to do so, at every opportunity\(^4\).

### 3.3 Use of telehealth and telemedicine

A 2011 Cochrane Review of telehealthcare for COPD\(^5\) found that telehealthcare in COPD appears to have a possible positive impact on the quality of life of patients and a reduction in the number of times they attend the emergency department and the hospital.

The Department of Health’s headline findings (2011) for the Whole System Demonstrator Programme\(^6\) state that: the early indications show that if used correctly telehealth can deliver a 15% reduction in A&E visits, a 20% reduction in emergency admissions, a 14% reduction in elective admissions, a 14% reduction in bed days and an 8% reduction in tariff costs. More strikingly they also demonstrate a 45% reduction in mortality rates. (This latter finding contradicts a 2010 Canadian systematic review which found an increased mortality rate in a telephone support group\(^7\), though it also found reduced hospitalisation rates and concluded that home telehealth interventions were similar or better than usual care for quality of life and patient satisfaction outcomes.)

In a telerehabilitation programme, well-managed interaction between patient (at home) and healthcare professionals (at, for example, a clinic) can lead to new relationships and improved learning processes\(^8\).
Early intervention with antibiotics and steroids can prevent admissions, but it can be difficult for patients to recognize the early signs of exacerbation and to access timely clinical care. There might be less benefit to use with patients whose COPD is stable\(^29\). One solution to these barriers to early management is the use of telemonitoring of symptoms and physiological signs\(^30\).

A range of telemedicine possibilities exists: medical consultations, in-home patient monitoring and remote rehabilitation. Teleconsultations can save time and travel costs for patients, with only a few still needing face-to-face consultations\(^31\). A nurse-initiated telephone follow-up programme was found to be effective in increasing self-efficacy in managing dyspnoea\(^32\). Tele home monitoring-based telenursing has been found to decrease significantly exacerbations and the use of healthcare services, with no effect on mortality\(^33\). In one study, telemonitoring was shown to have a positive effect on the quality of life of COPD patients\(^34\) but showed no evidence of reduced service utilisation. However another study showed that telemonitoring with daily spirometry led to a reduced number of hospitalisations\(^35\). Telehealth strategies that promote rehabilitation and early detection of an acute exacerbation have reduced hospital admission rates in people with severe and very severe COPD\(^36\). Weekly or monthly telephone calls and unscripted telephone coaching interventions appear to be most effective for improving self-management skills in people from vulnerable groups\(^37\). Although the use of real-time video telehealth (e.g. Skype) is relatively new, there is emerging evidence that it can reduce dyspnoea and can also lead to improved social support\(^38\).

A programme using telerehabilitation equipment (exercise bicycle, tablet computer with webcam and a pulse oximeter visible while teleconferencing) was found feasible for people with COPD, with patients showing significant improvement in the 6-minute walk distance and dyspnoea\(^39\).

A COPD telerehabilitation service comprising exercise training at home, telemonitoring and education/self-management led to reduced hospital costs, with no participants dropping out in over a year\(^40\). Pulmonary rehabilitation (PR) delivered via telehealth, with education sessions delivered on two days a week, was found to be an effective tool for increasing COPD pulmonary rehabilitation when there was insufficient PR capacity, leading to improvements in quality of life and exercise capacity comparable with standard PR\(^41\).

Although there have been studies suggesting that telemonitoring was not effective in postponing admissions\(^42\), many find that home-based telemonitoring has led to reduced hospital days and outpatient visits\(^33,44\) and improved health related quality of life\(^45\).

Real-time interactive voice and video telehealth (e.g. using Skype) has been found to be a feasible approach for teaching pursed-lips breathing in COPD, leading to improved social support and decreased dyspnoea\(^38\).
4 Addressing the barriers to implementation

4.1 Introducing telehealth

4.1.1 Barriers for health services

The introduction of telehealth into the healthcare setting has been recognized as a service that might be experienced as disruptive or even threatening. However, this can be overcome by employing simple yet effective measures such as: providing timely, appropriate and context-specific training; provision of adequate technical support; and procedures that allow a balance between the use of telehealth and personal visit by nurses delivering care to their patients. Staff involvement is essential in service redesign where telehealth is to be implemented.

The Nuffield Trust considered two possible impacts of telehealth on GP contacts: on the one hand, telehealth may lead to fewer contacts with the GPs as patient health is better controlled and there is less need for checking and monitoring – a reduction in demands on GPs; conversely, there could be a problem that more monitoring may lead to greater anxiety in patients, coupled with some ‘false alarms’ that increases the number of times they call upon their GP. They found that there was no change in contacts. It was also noted that the technology used in this trial did not allow routine sharing of information between the telehealth technology and GP records – something that should probably happen in an ideal world of integrated information systems.

4.1.2 Barriers for patients

There might be a difference between patients who adopt telehealth techniques and those who do not: greater disease severity might impact on patients’ ability to use it. The personal approach advocated should help to address this. The importance of risk stratification has been stressed. One review makes the point that there is as yet so much variation among studies that it is difficult to generalise results. Another study suggests that there might not be reduction in healthcare utilisation if patients are already receiving comprehensive respiratory care.

Concerns that older people might have difficulties with mobile telehealth-based applications appear to have been allayed. It has been found that patients are able to use the application, interpret clinical data, and use these within their self-management approach regardless of previous knowledge.

4.2 Delivering or enhancing self-management programmes

It is recognized that most individuals with COPD use several strategies to cope with their disease but health-care professionals need to ensure that evidence-based guidelines for COPD are translated to patients.
4.2.1 Barriers for health services

Lack of time of professionals has been mentioned as a barrier\textsuperscript{3,66}. A potential ensuing saving in time in GP contact, along with the savings in hospitalisations, could be offset against this. There are also specifically developed programmes available, so there is no need for staff to develop them themselves. The Self-management Programme of Activity, Coping and Education for Chronic Obstructive Pulmonary Disease (SPACE for COPD) manual was developed as the focus of a comprehensive self-management approach facilitated by health care professionals and has been shown to contribute significantly to improvements in exercise capacity and breathlessness\textsuperscript{58,59,60}. Similarly a ‘self-regulation protocol’ significantly assisted participants to control their individual symptoms (improved peak expiratory flow) and avoid acute exacerbation (lower rate of unscheduled physician visits)\textsuperscript{61}. Motivational Interviewing and Mindfulness for Health programmes have been found helpful in promoting behaviour change in COPD self-management programmes\textsuperscript{62}.

To save health professionals’ time, group sessions can sometimes be used. Simple education programmes aimed at large numbers of low risk patients (who might in time become high risk) might reduce the rate of breathing-related hospitalisation\textsuperscript{63}.

Some professionals might be aware that a minority of studies appear to show increased mortality associated with self-management in COPD\textsuperscript{64,65}. Reasons have not been confirmed (and research into this is said to be much needed) but is thought possible that the high risk patients involved might have needed earlier professional assessment or that self-management led to overconfidence and treatment delays. Appropriately delivered self-management training, including an individual approach, might ensure that this outcome does not occur.

Lack of training among staff in a practice is also a barrier to successful implementation\textsuperscript{3}, one which needs to be addressed. Again, the potential savings in hospitalisations can be offset against this.

4.2.2 Barriers for patients

Low literacy skills are associated with a variety of poor health outcomes and this might be a particular problem for patients with COPD who need to use inhalers appropriately. As well as literacy, cognition, intelligence, language and cultural barriers have been identified in some cases\textsuperscript{66,67}. Overcoming these will need consideration of a patient’s levels of these. A literacy-sensitive self-management intervention can lead to improvements in inhaler technique, maintaining quality of life and avoiding exacerbations\textsuperscript{68,69,70}. The personal or individual approach is recommended by many writers, concluding that frequent interaction, ‘health mentoring’, ‘hands-on guidance’ or nursing interventions based on individualised counselling are most likely to improve self-management and quality of life\textsuperscript{71,72,73,74,75,76,77}. 
These approaches might also be useful in terms of variation in patients’ attitudes over time: patients might feel differently about training depending on their physical and emotional state as they perform it. Patients also experience self-monitoring in different ways (encouraging, reassuring, depressing, worrisome or sometimes disturbing) so the personal approach from health professionals can ensure that this is a beneficial activity.

Community-based physiotherapeutic exercise programmes can be successfully incorporated into COPD self-management programmes to improve exercise capacity and to improve actual daily activity.

4.3 Delivering exercise programmes

4.3.1 Barriers for patients

Barriers to people with COPD exercising have been found to be the weather, followed by health problems and lack of intrinsic motivation, potentially overcome by increasing insight into health benefits, tailoring the type of activity and improving self-efficacy. Exercise training programmes are effective in improving exercise capacity, particularly when they also target behaviour change.

4.4 Use of social media

Although there has been, as yet, limited published evidence, studies have suggested that COPD education via YouTube could benefit patients. However, existing videos vary in content and quality, which might deter professionals from recommending them. To avoid missing out on the opportunity, professionals should direct patients to those produced by appropriate qualified medical professionals.

4.5 An holistic and multi-disciplinary approach

An holistic approach is much recommended, with a focus on living with the condition and its effects on life as a whole. This should include focusing on the patients’ fears associated with the uncertainty and progression of their disease. An educational approach alone is insufficient; changes in behaviour are also required.

Any approach to self-management must include attention to the patient’s family situation, including the perceptions of COPD by the family and the potential influence of care-givers (especially spouses, who have been found to improve adherence in COPD). There are examples of respiratory nurses focusing mainly on quitting smoking but advice is to widen this – to provide information on nutrition and exercise and to help patients to build confidence and become partners in the decision-making process.

It is recognized that there needs to be collaborative care between patients and health providers to promote good self-management. The Health Foundation suggests...
that the process of collaborative working in care planning involves finding out what is important to the patient, identifying the best treatment and supporting the patient in developing goals and deciding on the actions to achieve those goals.

5 The potential impact on patient outcomes

Whereas section 3 focused on different approaches and their effects, in this section we summarise the impacts from the patient’s perspective:

- Self-management and education programmes, including planned inhaler training, lead to:
  - Improved quality of life (e.g. health-related quality of life as measured by the St. George’s Respiratory Questionnaire (SGRQ))\(^{109,110,101,102,103,104,105,111}\).
  - Reduced frequency of attack\(^{111}\).
  - Reduced dyspnoea as measured by the Medical Research Council (mMRC)\(^{111}\).
  - Increased empowerment and coping skills.
  - Reduction in respiratory-related hospital admissions\(^{73,99,106,107,108,109,110,111}\).
  - High levels of self-efficacy, in turn associated with improvements in health-related quality of life, lower levels of breathlessness, lower levels of anxiety and lower levels of depression in COPD patients (although one study found no association between high self-efficacy and exacerbation rates\(^{112}\)). There is also greater level of understanding of the illness with higher self-efficacy and those with COPD might be empowered by being able to use cognitive coping skills\(^{113,114}\).
  - Programmes might also help to reduce depressive symptoms\(^{115,104}\).

Examples include: a one-year COPD programme with 30 hours of education and 16 hours of physical activity, following which there was a significant improvement during the intervention\(^{21}\); a brief nurse-led self-management intervention, which led to improvements in health-related quality of life\(^{8}\).

- Self-management programmes with exercise component lead to
  - Improved exercise capacity

- Pulmonary rehabilitation leads to
  - Improved exercise capacity\(^{116}\)
  - Reduced dyspnoea\(^{116}\)
  - Psychological well-being\(^{116}\)
  - Long term as well as short term benefits\(^{116}\).
• Exercise programmes lead to improved exercise capacity. For example, COPD patients who undertake an activity equivalent to walking 60 minutes a day halve their risk of being admitted as an emergency admission irrespective of their severity, nutritional status or respiratory rehabilitation.

• Exercise and lifestyle programmes, including stopping smoking, leads to
  - Reduced respiratory-related unplanned hospitalisation

• Use of teleconsultations leads to
  - Reduced visits to primary care
  - Saving time and travel costs

• Self-management and routine monitoring can lead to patients becoming more capable of appropriately managing exacerbations.

6  Cost-effectiveness

Pulmonary rehabilitation has been found to be the most cost-effective treatment in severe disease. Stop smoking interventions are highly cost effective for those with mild-to-moderate COPD and are the most effective for those with undiagnosed COPD. Exercise programmes are very cost-effective for mild-moderate COPD sufferers.

Chronic respiratory patients requiring oxygen or home mechanical ventilation experience frequent exacerbations and hospitalisations with related costs. Tele-assistance for COPD patients has been shown to reduce hospitalisations, urgent GP calls and exacerbations, along with associated costs.

Although one 2004 study suggested that COPD self-management programmes were not cost efficient for moderate to severe COPD patients who rate their health-related quality of life relatively high, there are many more examples in which COPD self-management education programmes have been shown to be cost-effective, reducing the levels of hospitalisation. The effectiveness is greater as caseloads increase and is likely to become more pronounced as hospital costs rise. Economic analysis suggests that with thresholds of 20,000 or 10,000 per quality-adjusted life-year gained, self-management interventions are likely to be cost-effective, potentially meeting NICE cost-effectiveness criteria.

7  Emerging recommendations for the NHS around self-management

Taking self-management in its widest sense, the following summarises the recommended actions derived from the findings outlined above:
• Create a self-management plan to be used alongside a multi-faceted self-management program.
• Educate patients with COPD about:
  o effective inhaled therapy
  o exacerbation, including recognition of severity of symptoms
• Promote (and provide) pulmonary rehabilitation to all who need it.
• Educate all patients with COPD about the benefits of
  o stopping smoking – and offer appropriate help at every opportunity.
  o Exercise – and ensure programmes or opportunities are available.
• Use an holistic approach – taking into account all aspects of the patient’s life and circumstances.
• Work with patients with COPD and their families in a collaborative manner. Ensure programmes are tailored to address literacy, cognition, intelligence, language and cultural barriers.
• Use telehealth where possible.
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