



# Policy position statement

Chronic Obstructive Pulmonary Disease (COPD) - May 2017

## Introduction

The British Lung Foundation recommends:

- **Improvements to COPD diagnosis speed and accuracy** through better symptom awareness amongst the public and healthcare professionals, wider use of quality-assured spirometry, structured assessments and access to specialist care.
- **Better access to treatments** which are cost effective such as pulmonary rehabilitation, stop smoking services, flu and pneumococcal vaccination, inhaler medication and oxygen therapy.
- **Improvements to data collection and coding for diagnosis and treatment** to ensure accurate diagnosis and better assessment of the quality and suitability of services.
- **Better identification of palliative and end of life care needs**, with holistic needs assessments and individual tailoring.
- **More supported self-management and peer support**, with a focus on building skills, knowledge and confidence for sustainable behaviour change.

The policy objectives summarised above were informed by the recent National COPD Audit, a range of research, as well as British Thoracic Society (BTS) and NICE guidance. The evidence base is largely England/Wales focused due to limited research, but should help inform policy in all UK nations.

### What is COPD?

COPD is an umbrella term for emphysema and chronic bronchitis. Emphysema involves air sac (alveoli) deterioration. Chronic bronchitis is airway (bronchi) inflammation and damage. Symptom presentation and severity varies, but typical features are breathlessness, cough and sputum production.

### How many people live with COPD?

Around 1.2 million people in the UK have a COPD diagnosis. Incidence and mortality rates are 115,000 and 30,000 people per year.<sup>1</sup> There is some uncertainty over the number undiagnosed, but NHS England estimates around two million people.<sup>2</sup> Prevalence is predicted to increase as more women develop COPD.<sup>3</sup> Forecasts indicate that despite falls in smoking rates, COPD incidence will not decline in the near to medium term, due to an ageing population.<sup>4</sup> Prevalence, incidence and mortality rates are highest in Scotland and northern England, correlating with high smoking rates.<sup>5</sup> UK prevalence is around 2.5 times greater - and incidence 2.2 times higher - in the most deprived quintile than the least.<sup>6</sup> This largely reflects higher rates of smoking among deprived groups; COPD is predominantly, but not exclusively, caused by smoking.<sup>7</sup> Other risk factors include occupational risks, second-hand smoke and low birthweight.<sup>8</sup> Alpha-1 antitrypsin deficiency is a causative factor in 1%-5% of people with COPD.<sup>9</sup> COPD is progressive and severity increases with age. Around 80% of people with COPD have at least one comorbidity - commonly cardiovascular disease and diabetes.<sup>10</sup> Under 1% of people who have COPD are under 40, with over 80% of diagnoses in people over 60.<sup>11</sup>

### What is the impact of COPD?

COPD is the UK's fifth biggest killer.<sup>12</sup> It accounts for over 140,000 hospital admissions and over a million bed days each year - around 97% of admissions are for emergency care.<sup>13</sup> Annual COPD direct health costs (excluding work days lost etc.) in England were estimated to be £1.9 billion in 2013-14.<sup>14</sup> Other economic research has predicted that the direct health costs of COPD will increase to £2.32 billion in 2030.<sup>15</sup> The cost of COPD in Scotland is also estimated to increase from £159 million to £207 million by 2030.<sup>16</sup>

## What are COPD exacerbations?

Exacerbations are a sustained and sudden worsening of symptoms triggered by infections or environmental factors, including pollution.<sup>17,18</sup> UK data shows 26.2% of people with COPD had one exacerbation prior to diagnosis, and 25.5% had over one.<sup>19</sup> People with the most severe COPD experience nearly three times more exacerbations than the least severe.<sup>20</sup> The average hospital stay is four days; inpatient mortality was 4.3% in 2014.<sup>21</sup> Women made up 51% of emergency admissions in 2014, up from 49% in 2008 and 47% in 2003.<sup>22</sup> A severe exacerbation costs the English NHS on average £3,726 and the Scottish NHS £3,329.<sup>23</sup>

## Key recent developments

The National COPD Audit Programme is currently exploring the English and Welsh provision of COPD interventions and possible improvements. It is led by the Royal College of Physicians in partnership with other organisations, including the BLF. There are five workstreams, exploring primary care, secondary care, pulmonary rehabilitation, resources, and data.<sup>24</sup> The primary care workstream has focused on Wales due to limitations on data extraction from English practices. Several broad improvement areas identified are: **speed and accuracy of diagnosis; referral to, and the quality of, specialist treatment; and variations in data collection and coding.**

These improvement areas correspond well with the BLF's campaigning activity. We have recently focused on highlighting breathlessness as a sign of lung disease, calling for changes to the NHS Health Check to include questions on lung function, calling for respiratory taskforces in England and Scotland, extensions and strengthening of existing respiratory strategies in Wales and Northern Ireland, as well as calling for improvements to data recording, collection and analysis across the UK.

## Policy objectives

### Improvements to the speed and accuracy of COPD diagnosis

We want to see improvements in the speed and accuracy of COPD diagnosis. We are calling for:

- Increased awareness amongst the public of breathlessness as a symptom of lung disease.
- Better and more widespread training for healthcare professionals to identify the signs of COPD.
- Improved access to specialist care, notably respiratory nurses and respiratory consultants.
- Widespread use of structured assessments for diagnosis.
- Mandatory requirements for clinicians to ask questions on respiratory health as part of the NHS Health Check, with better compliance with guidance on assessing patients presenting with COPD symptoms.
- Those performing spirometry to be certified in a national register for their competence.<sup>25</sup>

Greater public awareness of the significance of COPD symptoms should encourage visits to general practice sooner in the patient's journey. Training for healthcare professionals should enable quicker diagnosis and/or referral for further treatment. Spirometry and structured assessments can inform clinical judgement and provide more definitive diagnoses,<sup>26</sup> in the absence of a single diagnostic test for COPD.<sup>27</sup> Early diagnosis and treatment can slow disease progression and improve quality of life.<sup>28</sup>

There is scope for improving early diagnosis:

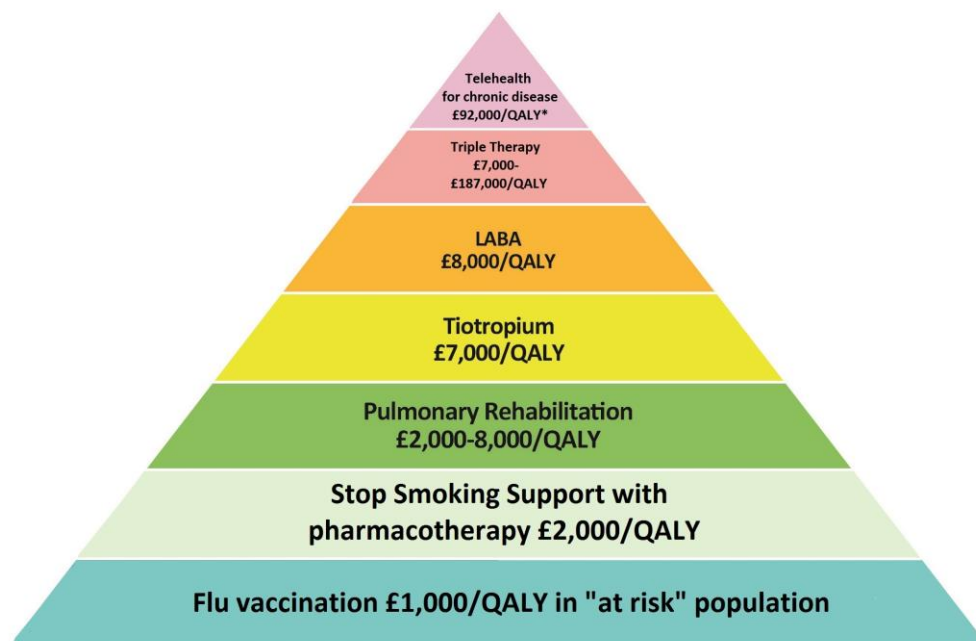
- Over 15% of people in England are only diagnosed during an emergency admission.<sup>29</sup>
- A recent study of over 38,000 people with COPD in the UK found that opportunities for diagnosis were missed in 85% of patients in the five years before their diagnosis.<sup>30</sup>
- 7% of people in England and Wales **admitted** to hospital with a COPD exacerbation had no prior diagnosis (as opposed to the 26.2% who **experienced** one exacerbation prior to diagnosis).<sup>31</sup>
- Only 46% of patients in English and Welsh acute units had evidence of spirometry being recorded within the last five years - down from 54% in 2008.<sup>32</sup>

## Better access to treatments - high value, low cost interventions and other treatments

We want people with a diagnosis of COPD to have access to effective treatments and care, with tailored care bundles in primary and secondary care, appropriate for them. Treatments and care options include high value, low cost interventions such as pulmonary rehabilitation, stop smoking services and flu vaccinations. Inhaled therapy and oxygen should be prescribed where appropriate. Social care needs must also be assessed. All services and treatments should be commissioned in a fully integrated manner with clear pathways engaging primary and secondary care, in line with national guidelines.

NHS England's London Respiratory Team developed the COPD 'Value' Pyramid, outlining the cost effectiveness of each intervention by quality adjusted life years (QALYs) - a measurement of how many years of perfect health each intervention offers, and for what cost.<sup>33</sup>

Below is an overview of our position on each intervention by policy priority, and the COPD pyramid itself.



### Pulmonary rehabilitation

We want people with COPD to have better access to pulmonary rehabilitation (PR). We are calling for:

- Robust referral pathways and capacity for PR programmes to recruit all patients within three months of receipt of referral (one month for patients hospitalised for acute exacerbations, due to increased need).
- Improved capacity within healthcare and community settings for PR, held at suitable times and places.
- Full compliance with British Thoracic Society (BTS) standards for PR delivery and assessment.
- More flexibility in PR programmes to ensure that patients referred complete their treatment.
- People who complete PR to be given written, individualised plans for ongoing self-management and maintenance exercise, as well as access to places to exercise, which will enable them to continue their exercises.

PR is a six to eight week multidisciplinary programme of supervised exercise classes and education designed to improve physical function, improve confidence to exercise and create sustained behaviour change around physical activity and self-management. PR is beneficial for patients who are functionally limited by their condition,<sup>34</sup> but still able to walk.<sup>35</sup> PR reduces COPD-related levels of anxiety and depression.<sup>36</sup> PR is high value and cost effective, resulting in reduced readmissions, and helping save lives.<sup>37</sup> Only four patients need to take part in a course of PR to prevent one re-admission to hospital, with the positive effects of increased exercise tolerance generally lasting about a year.<sup>38</sup> In England

and Wales, 57% completing a course of PR performed better than the minimal clinically important difference for the incremental shuttle walk test and 70% for the 6-minute walk test.<sup>39</sup>

There is scope for improving PR services. The COPD Audit's PR workstream in England and Wales found:

- For every 100 people with COPD who are referred for PR, 69 will receive a suitability assessment, 59 will be enrolled and just 42 will complete their course.<sup>40</sup>
- 37% of people with COPD wait longer than the recommended three months for PR after referral.<sup>41</sup>
- This means that only around 26% of all people with COPD referred for PR will complete their course within the recommended time.

## Stopping smoking

We want people with COPD who smoke to be referred to specialist stop smoking services. We also want:

- Healthcare professionals to be trained to ensure that they are confident to empower people to stop smoking, and can use exhaled carbon monoxide monitors at each contact.
- All healthcare professionals seeing patients with COPD to undergo training through the National Centre for Smoking Cessation and Training (NCSCT).
- Commissioners to recognise the value of stop smoking services and ensure their continued provision for people with COPD, despite ongoing local authority budgetary pressures.
- Greater use of pharmacotherapy and effective use of nicotine replacement therapy (NRT).
- E-cigarettes to be offered to those unsuccessful in quitting with conventional therapies offered through part of stop smoking services programmes
- Stop smoking services to be targeted at high risk groups - such as those with mental health problems and homeless people, with support offered to all inpatients at all stages of care

Stop smoking services are the responsibility of local authorities. They offer help for people to stop smoking, with quit attempts four times more likely to be effective with this support. They provide information and advice to help smokers quit and give support during the first few months of stopping smoking, offering pharmacological solutions such as NRT and medicines such as varenicline.

Stopping smoking is important as it leads to improvements in COPD symptoms and delays disease progression. Stopping smoking at age 30 can lead to 10 years extra life expectancy, with quitting at age 60 leading to three more.<sup>42</sup> E-cigarettes, which studies suggest are around 95% less harmful than regular cigarettes,<sup>43</sup> may have helped around 18,000 people in England give up smoking in 2015.<sup>44</sup>

There is considerable scope for improving stop smoking services:

- Only 58% of smokers in England and Wales received smoking cessation advice during their admission to hospital, with wide variation across sites.<sup>45</sup>
- The number of people using stop smoking services in England declined to 382,500 in 2016-16, with 15% fewer people setting a quit date in 2014-15, and 37% fewer than 2005-06. NHS Digital suggested this may be due to increased e-cigarette usage,<sup>46</sup> while others have noted that budgetary pressures have led to cuts to stop smoking service budgets.<sup>47</sup>
- 33.5% of people with COPD in Wales smoked in 2014,<sup>48</sup> compared to 20% of all people in Wales.<sup>49</sup>
- In Wales, 74.3% of people with COPD who smoked were referred to stop smoking services, but only 10.8% received pharmacology to alleviate tobacco dependency.<sup>50</sup>
- COPD patients' smoking status in Wales is not always recorded annually, despite relapse risk.<sup>51</sup>

We also support targeted approaches to prevent the most at risk groups from taking up smoking. This includes less affluent communities and young people, people with mental health problems, homeless people, former smokers at risk of relapse and pregnant women.

## Flu and pneumococcal vaccinations

We want healthcare professionals to ensure that people with COPD receive the free annual flu vaccination that they are entitled to, as recommended in NICE guidelines.<sup>52</sup> We also want people with COPD to receive a pneumococcal vaccination to protect them from pneumococcal infections. Some people will require a single vaccination to protect them for life, while others may need them on a five-yearly basis.<sup>53</sup> We want reductions in regional variations of uptake, through targeted campaigns. Primary care practitioners (GPs and practice nurses) must not exception-code COPD patients for flu vaccinations (i.e. register COPD patients as not requiring them). This supports the vaccination of COPD patients on an annual basis.

Vaccinations can reduce the number and severity of acute exacerbations in those with COPD, which in turn may reduce the chance of hospitalisation.<sup>54</sup> It has been recognised by NHS England to be one of the most cost effective preventative treatments for COPD, as outlined in the COPD Value Pyramid.<sup>55</sup>

There is some scope for improving uptake of the flu vaccination. It is underutilised as an intervention - one in five people on the Welsh COPD register were recorded as not vaccinated in 2014-15.<sup>56</sup> Evidence also suggests regional variation in vaccine uptake in Wales, without explanation as to why.<sup>57</sup>

## Inhaler therapy and medication

We want healthcare professionals who prescribe inhalers to people with COPD to ensure that these patients know how to use their device correctly. In line with guidance on inhaler standards and competency,<sup>58</sup> healthcare professionals should:

- Prescribe only when patients know how to use their device, through observation.
- Ensure an assessment of continued need and ability, with review dates planned.
- Give advice on care, maintenance and storage.
- Audit the number and frequency of inhalers prescribed and collected by patients.

An inhaler is a medical device which delivers medication into the lungs via the mouth. A bronchodilator is a medicine that dilates the bronchi and bronchioles, decreasing airway resistance and increasing lung airflow. There are two main classes of inhaled bronchodilators: beta-2 agonists (called “LABA” if long acting) and antimuscarinic (also known as anticholinergic) agents (called “LAMA” if long acting). Inhaled corticosteroids (ICS) are an anti-inflammatory medicine.

We also want healthcare professionals to only prescribe appropriate bronchodilator medications. Healthcare professionals must be aware of the safety issues around long-term high dose inhaled steroids, and prescribe inhaled corticosteroids for patients only for whom are likely to be benefit.

There is scope for improving the utilisation of inhalers:

- 43.8% of people with COPD using inhaler therapy in Wales received an inhaler technique check in the last 12 months.<sup>59</sup>
- 91.3% of people with COPD in Wales have had an inhaler check at any point since diagnosis.<sup>60</sup>

## Oxygen therapy

We want safe and appropriate prescribing of oxygen therapies for people with COPD. This includes:

- Rolling training programmes for healthcare professionals on prescribing oxygen, to ensure the oxygen prescriptions for people with COPD are only made when clinical benefit is clear.
- Commissioners ensuring people with COPD receive regular formal oxygen therapy assessments by respiratory specialists - ideally in their own homes.
- Ensuring that the commissioning of oxygen is linked with local/national payment incentives.

- Non-invasive ventilation (NIV) being offered to those with acute exacerbations who do not respond to optimal treatment<sup>61</sup>, and delivered in a dedicated setting by trained and experienced staff, as the equipment can be dangerous.
- Home oxygen therapy prescribed to address low blood oxygen levels,<sup>62</sup> but only when used for at least 15 hours a day - ideally 20 hours a day to see greater benefits.<sup>63</sup>
- Referring people who require oxygen to stop smoking services as a priority intervention.<sup>64</sup>
- Preventing oxygen prescription at excessive flow rates, especially during acute exacerbations, as this may cause dangerous increases in CO<sub>2</sub> levels.<sup>65</sup>

Use of long term oxygen therapy (when used for 15 hours a day) is associated with lower mortality rates.<sup>66</sup> Around 85,000 people in England receive oxygen at home, costing £110 million annually.<sup>67</sup> People with COPD may be required to receive NIV in clinical settings (such as during acute exacerbations). Inappropriate oxygen therapy is extremely wasteful and potentially hazardous.

There is scope for improving the provision of oxygen therapy services:

- Around 30% of people prescribed oxygen neither use nor benefit it, due to misprescribing.<sup>68</sup>
- Around 20% of people with COPD would benefit from oxygen therapy but do not receive it.<sup>69</sup>
- Emergency oxygen therapy prescription rates in England and Wales vary depending on whether they have been seen by a respiratory team - 60% with compared to 42% without.<sup>70</sup>
- 55% of COPD inpatients in England and Wales were prescribed oxygen - well below the 84% target.<sup>71</sup>

### Improvements to data collection and coding for COPD diagnosis and treatments

We want to see healthcare commissioners and providers improve data collection, education and coding for COPD activity in all healthcare settings. We are calling for:

- Patients to be enabled to record quality of life assessments and document their self-care.
- Commissioners to ensure that there is a uniform electronic coding system for recording COPD activity. Healthcare professionals should be able to access this easily.
- Healthcare professionals to be trained certified on recording and interpreting spirometry results, for inclusion in the national register of certified spirometry operators.<sup>72</sup>
- Improved recording of key information on each admission (and for PR assessment), including: confirmation of exacerbations on spirometric evidence; the presence/absence of chest x-rays; a Medical Research Council (MRC) breathlessness score in the weeks prior to the current exacerbation; initial oxygen saturation; blood gas at one, four and 12 hours after the initiation of NIV; and DECAF score components.

Data collection involves recording relevant medical data - such as patient information and interventions offered - in a standardised and shareable manner. Good data collection highlights the overuse and underuse of interventions and ensures appropriate services are provided to patients. It should support more accurate diagnosis, allowing better judgment of the safety and suitability of interventions such as PR, as well as expensive and potentially harmful interventions such as oxygen therapy.

There is considerable scope for improvement in data coding and recording for COPD across all settings.

In primary care:

- Only 46% of patients admitted for exacerbations in England and Wales had their spirometry data recorded in 2014, compared with 54% in 2008 and 55% in 2003.<sup>73</sup>
- There was significant variation in the percentage of patients in Wales with a post-bronchodilator FEV1/FVC ever recorded in 2014/15 - ranging from 5.4% to 39.3% between regions.<sup>74</sup>

- Around 80% of people on the COPD register in Wales do not have an electronic record of post-bronchodilator FEV<sub>1</sub>/FVC ratio - the principle diagnostic test for COPD.<sup>75</sup>
- The COPD primary care audit in Wales found low recording rates of key metrics such as oxygen prescribing. The authors suggested that this could reflect confusion about appropriate coding.<sup>76</sup>

In secondary care:

- In England and Wales in 2015, 59% of patients admitted for an exacerbation did not have their body mass index (BMI) recorded, with BMI recorded in just 66% PR assessments.<sup>77</sup>
- The MRC breathlessness score in the weeks leading up to hospital admissions for exacerbations in England and Wales in 2014 were recorded poorly - only 61% of cases.<sup>78</sup>
- There was poor recording of variables required to calculate the DECAF score for exacerbations, which is predictive of mortality and length of stay.<sup>79</sup>

In community care:

- Spirometry was used in 62% of PR assessments in England and Wales in 2015.<sup>80</sup>

### Improved identification and delivery of palliative and end of life care needs

We want to see palliative and end of life care needs considered more systematically within the journey of each person with COPD, in coordination with their family and carers. We are calling for:

- Healthcare professionals to be provided with training, expertise and confidence to provide a holistic needs assessment and support for patients requiring palliative care.
- People with COPD to be offered frequent holistic needs reviews to identify when it is appropriate to discuss palliative care and end of life needs.
- Healthcare professionals to provide non-pharmacological management techniques that help people with COPD and their families and carers better manage their COPD.
- Recognition that unlike cancer, there is no clear transition point for COPD to end of life care.

There is scope for improving end of life care for people with COPD: 69% of people who die from all respiratory diseases - including COPD - die in hospital, with only 13% at home. This is more than any other disease area.<sup>81</sup> Research shows that the abrupt and unpredictable end of a person's COPD journey means that current models of palliative care must be adapted.<sup>82</sup> More tailored palliative care following a holistic needs assessment will allow people's physical and emotional needs to be better met, enabling them to die with dignity, with greater control of their circumstances, and in a place of their choice.

### Supporting, promoting and carrying out self-management and peer support

We want healthcare professionals to provide advice, guidance and support to people with COPD to enable them to self-manage their condition. Patients must be made aware that the responsibility for day-to-day self-management is theirs. Patients should still receive support from a healthcare professional,<sup>83</sup> with patients advised to contact a healthcare professional if their condition does not improve.<sup>84</sup> Written self-management plans and guidance must be provided, these must:

- Be tailored for literacy, cognition, language and cultural barriers, to improve skills and confidence in managing their condition, independent of healthcare professionals.
- Include suggestions on improving motivation in patients through setting valued goals and improving management skills.
- Include information on how to manage breathlessness, including mastering effective breathing and sputum clearance techniques, and recognising early signs of exacerbations.
- Outline how to access stop smoking services.
- Outline the value of exercise, signposting towards programmes that support their own self-management. These may include interventions targeted at improving physical, emotional and social health, such as exercise and singing.<sup>85</sup>

Self-management interventions are structured and personalised approaches which motivate, engage and support the adoption of healthy behaviours, with the development of skills to better manage conditions. These interventions are often multicomponent.

We want healthcare professionals to refer patients to local Breathe Easy support groups. These groups provide people with peer support, helping provide them with the skills, confidence and knowledge to self-manage their condition better. An evaluation of Breathe Easy groups and Integrated Breathe Easy groups (groups which are fully integrated with the local care pathway) found that, of those who attended standard Breathe Easy groups:

- 90% have a better understanding of their lung condition
- 88% felt more confident in managing their lung condition
- 85% knew more about services for people with lung disease in their local area
- 61% do not feel the need to visit their healthcare professional as often as before<sup>86</sup>

There is scope for improving access to support groups. A web community poll by the BLF found that, of 433 respondents, 18.7% did not have a Breathe Easy group available in their area and 24.7% had not heard of Breathe Easy groups.

Self-management support is not being implemented into routine clinical practice. A 2012 study found that although there is strong support amongst healthcare professionals for self-management in England, it was only discussed with 55.1% of people with COPD, with only 47.8% receiving a written action plan.<sup>87</sup> This was due to time constraints, lack of training, lack of belief in patient ability, and a lack of confidence in healthcare professionals completing self-management plans.<sup>88</sup>

The evidence of the effectiveness of self-management support is developing. A Cochrane Review of self-management for patients with COPD found that these interventions reduce admissions and improve quality of life. Moreover, a study in England found that patients with self-management support were more capable of appropriately managing exacerbations than those that did not.<sup>89</sup> NICE removed a national recommendation for people with COPD to have an individualised management plan in 2016, but suggested it may be useful at a local level.<sup>90</sup>



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