

Failing on the fundamentals

Insights from those living with chronic obstructive pulmonary disease (COPD) around the UK

November 2021



Contents

Foreword	3
Executive summary	4
Headline survey findings	6
Introduction	7
Chapter one	
COPD diagnosis – delays and missed opportunities	9
Chapter two	
COPD care – low standards and huge variations	13
Chapter three	
What does it mean to live with COPD?	20
Chapter four	
Perceptions of COPD – misunderstood and left behind	23
Concluding remarks	25
About the survey	25
What people with COPD can do	26
Appendix A	
References	27
Appendix B	
Survey questions	29
Appendix C	
Data tables	35

Foreword

This is a landmark survey on Chronic Obstructive Pulmonary Disease (COPD), the largest ever conducted of people in the UK. It offers unparalleled insight into the lived experience of people with COPD, and exposes unacceptable levels of delayed diagnosis and absent care, while illustrating the challenges people face living with this common, debilitating lung condition. Urgent change is needed for the more than 1.3 million people in the UK with a diagnosis of COPD, as well as the huge numbers of people with the condition who are yet to receive a diagnosis.

If around half of cancer cases went undiagnosed, it would be a national scandal. This is exactly the situation with COPD. We found significant delays in diagnosis, and estimate that at least 46,000 people missed out on a diagnosis of COPD in 2020 as a result of the pandemic. As we approach the end of 2021 diagnostic services are not yet back up and running, meaning that tens of thousands are likely to face the same problem. We cannot let history repeat itself.

Our survey found that even if a patient has a confirmed COPD diagnosis, it's likely they'll struggle to access the care they need – 75% of those we asked are missing out on the very basics. This is what NICE has defined as the “five fundamentals of COPD care” – a written self-management plan, access to pulmonary rehabilitation, assistance to stop smoking, identification and management of coexisting medical conditions and flu and pneumonia vaccination. Not only is this causing untold pain for families across the country, but it means that far more people are ending up in hospital putting a significant burden on our health service.

It's clear that we cannot carry on like this. If governments across the UK are to build back fairer after the pandemic, they must prioritise COPD and other respiratory conditions. As a first step, we need rapid investment to help respiratory services get back on their feet, especially in primary care, and for each nation to put in place a fully funded lung health strategy that prioritises the backlog.

Looking to the future, there's so much more we can do to prevent people developing COPD in the first place – whether it's action on air pollution, smoking, childhood deprivation or reducing exposure to dust and harmful fumes in the workplace. Policy change on these issues will be crucial if we are to level up health inequalities for a condition with stark disparities.

COPD is a progressive condition and there is currently no cure. But through research there's hope that we will one day develop ground-breaking diagnostics and treatments. We have seen what investment in Covid research has achieved, delivering new vaccines and treatments. That hasn't happened by magic. There is a direct correlation between investing in research, the people and the laboratories and finding answers.

People living with COPD have been forgotten and left behind by health systems for too long. This survey has shed light on their experiences and must catalyse improvements in COPD diagnosis and care. At the BLF we will be working hard to make sure that policy makers around the UK cannot ignore its findings. My hope is that by our next survey in 2022, we will already have seen significant improvements for the millions of people living with COPD.



A handwritten signature in black ink, appearing to read 'Sarah Woolnough'.

Sarah Woolnough
Chief Executive, Asthma UK & British Lung Foundation

Executive summary

Chronic obstructive pulmonary disease (COPD) is the name for a group of lung conditions that cause breathing difficulties and a permanent narrowing of the airways. It is the fifth most common cause of death in the UK, resulting in 30,000 deaths per year¹. More than 1.3 million people in the UK have a diagnosis of COPD and it is estimated that at least a similar number of people have the condition but are as yet undiagnosed². In the absence of treatment those without a diagnosis are at risk of deteriorating health and quality of life, with later diagnosis linked to higher levels of COPD exacerbations and a greater chance of dying from the disease³.

Thousands missing out on diagnosis

The BLF conducted this survey of over 8,000 people with COPD between December 2020 and May 2021. Even before the pandemic, it is clear from the responses that many people with COPD had experienced unacceptable delays before a diagnosis was made. During this period, the impact of COVID-19 considerably worsened people's daily lives, their chances of being diagnosed, and the level of care they received. Recent government figures found that diagnosis rates – which were already far too low – plummeted even further. In 2020 there was a 51% reduction in COPD diagnosis compared to 2019, meaning that around 46,000 people missed out on a diagnosis in England alone, a much higher drop than seen for comparable conditions, such as diabetes⁴.

As of November 2021, diagnostic tests such as spirometry have not yet properly resumed, making it likely that a further 46,000 people in England may have gone undiagnosed in 2021. While rates of cancer diagnosis are already up to, and in some areas better than pre-pandemic levels⁵, there is no dedicated plan to address the huge backlog in respiratory care. In all four nations, we want to see respiratory plans address this issue urgently.

75% of people with COPD are not receiving basic care

We found that across the UK, over three quarters (75.5%) of those with COPD did not receive what NICE clinical guidance defines as the five fundamentals of COPD care (a basic level of care comprising elements such as provision of a self-management plan, vaccinations against flu and pneumonia, referral to smoking cessation services, pulmonary rehabilitation and managing other co-existing medical problems). Receipt of these five fundamentals was more likely when more time had passed since the initial diagnosis. This may be because people with COPD have to learn how to navigate the NHS to get the care that they need, and this is time during which their health may deteriorate considerably. Alternatively, it may be that healthcare professionals do not prioritise treatment until a patient has deteriorated. Neither scenario is acceptable.

Isolated and left behind

Our survey suggests that around 420,000 people have had their working lives cut short by COPD, and that it has held them back from socialising and pursuing leisure activities. For over half of people asked their mental health has worsened since receiving a diagnosis. Despite the devastating impact of COPD, and the relatively high prevalence of the condition, it remains misunderstood by the media and the general public. Over a quarter of our survey respondents (27.9%) told us they had faced direct discrimination since being diagnosed with COPD, and many shared stories of social isolation, ostracism and reduced opportunities.

Change is urgently needed and critical for any plan to level up health disparities

We are calling on governments and health services across the four nations of the UK to:

- **Rapidly commit funding for national health services to get lung health strategies back on track and tackle the respiratory backlog.** While respiratory conditions are supposedly a clinical priority, this does not seem to be the case in practice, and we need to see ambitious targets for improving COPD prevention, diagnosis and care. In England and Scotland this means getting back on track with the respiratory ambitions set out in the NHS Long Term Plan and the Respiratory Care Action Plan respectively, and national health services must work with clinicians and patients to develop a new Respiratory Health Delivery Plan in Wales and a Lung Health Strategy in Northern Ireland as an urgent priority.
- Transform COPD diagnosis by:
 - Prioritising the urgent **restart of spirometry testing in primary care** for the diagnosis of COPD and other respiratory conditions across the UK.
 - Rolling out **national breathlessness pathways** to improve diagnosis and access to treatment in all UK nations.
 - Implementing **Community Diagnostic Centres (CDCs)** in England supported by multi-year investment and clearer guidelines on how CDCs should operate, so that Primary Care Networks can get them up and running as soon as possible.
 - Amending guidance for GPs across the UK to ensure **proactive case find amongst high-risk groups to identify those at high risk of developing COPD** and other lung conditions such as idiopathic pulmonary fibrosis and lung cancer.
- Improve care for people with COPD by:
 - Ensuring everyone with COPD is offered **all five fundamentals of care for COPD – at diagnosis and at routine reviews – by including them as indicators in the Quality Outcomes Framework (QOF)** for general practice across all four nations.
 - Urgently **restarting pulmonary rehabilitation services** that are still yet to resume. This must be supported by additional investment in all UK nations to ensure services can meet increased demand for PR stemming from people with Long COVID-related breathlessness and those with pre-existing respiratory conditions who may have deconditioned throughout lockdowns.
 - **Expand access to pulmonary rehabilitation** to those with milder COPD, and improve signposting for patients, so all those who could benefit have access to it across the UK.
- Reduce health inequalities by:
 - Ensuring **disparities in COPD prevalence, diagnosis and care are a major part of national health inequalities strategies**, with concrete targets in place and clear plans for how to reach them.
 - Properly implementing **very brief advice (VBA) for smoking cessation across primary care** and making it a core part of undergraduate and postgraduate medical training, with a focus on delivery for those with respiratory conditions.
 - Ensuring hospitals **deliver the “Ottawa Model” for smoking cessation** to support people admitted to quit smoking.

Headline survey findings



Chapter one

COPD diagnosis – delays and missed opportunities

- Identification of COPD is poor, with 14.4% of respondents reporting an initial misdiagnosis, 21.7% having their symptoms mistaken for a chest infection or cough, and 3.2% being sent away by their GP after raising their COPD symptoms.
- 60.6% of respondents did not feel that they had enough support and knowledge to manage their COPD post diagnosis, and only 42.2% remembered receiving written support materials to support their new diagnosis, despite NICE specifying that all patients with COPD should receive this.



Chapter two

COPD care – low standards and huge variations

- Across the UK, over three quarters (75.5%) did not receive the five fundamentals of COPD care as set out in NICE clinical guidelines.
- The situation is even worse in the devolved nations. In Northern Ireland only 13.5% of people received the five fundamentals of care, while in Scotland the figure is 17.2% and in Wales 17.4%.
- Those with a recent diagnosis were most likely to receive the lowest levels of care and there is a clear relationship between length of time since diagnosis and receiving the five fundamentals of COPD care.
- Respondents who reported receiving the basic standards of COPD care had fewer exacerbations, were better able to self-manage their condition, and better understood what to do when their symptoms worsened.



Chapter three

What does it mean to live with COPD?

- An estimated 420,000 people in the UK may have had their working lives cut short by COPD.
- Over half (56.1%) of respondents told us their mental health had worsened since receiving a COPD diagnosis.



Chapter four

Perceptions of COPD – misunderstood and left behind

- COPD is misunderstood among the wider public. Nearly half (46.3%) of respondents thought that people thought badly of them because they had COPD while 27.9% told us they had faced direct discrimination since they were diagnosed.

Introduction

The findings in this report are from the largest survey of people with COPD ever conducted in the UK. We found that thousands of people living with COPD are receiving substandard care and being left to navigate their own way through complicated and disjointed health systems to get the support they need.

But there is hope. There's clear evidence that securing a speedy diagnosis and receiving the basics of care can significantly improve outcomes for patients, transforming lives and reducing the burden on the NHS. We know that the five fundamentals of COPD care are essential and highly cost-effective interventions for the NHS to deliver. Yet even before health services had to contend with the pressures of COVID-19, far too many people with COPD were being let down and left behind. Now we understand the full picture, it's time to change this.

What is COPD?

Chronic obstructive pulmonary disease (COPD) is the name for a group of lung conditions that cause breathing difficulties. These lung conditions include emphysema and chronic bronchitis. COPD is a permanent narrowing of the airways. It is a progressive condition but can be controlled with treatment and self-management. Symptoms of COPD include:

- getting short of breath easily when you do everyday things such as going for a walk or doing housework;
- having a cough that lasts more than a couple of weeks;
- wheezing in cold weather; and
- producing more sputum or phlegm than usual⁶.

COPD is a common condition that mainly affects middle-aged or older adults who smoke or have a history of smoking⁷. However, many people who have never smoked have COPD; it can also be caused by exposure to air pollution, or occupational exposure to harmful fumes or dust, and genetics can also play a role.

The diagnosis of COPD should include a discussion about smoking, work and lifestyle history and several tests, including spirometry, chest imaging and a blood test (which are often used to rule out other conditions, such as lung cancer). As well as affecting breathing, living with COPD often means reduced physical activity, and many people with COPD report a significant impact on their mental health.

Living well with the condition

There is no cure for COPD, but there is effective treatment to alleviate symptoms and slow down disease progression. Once diagnosed, people with COPD should receive support and advice on stopping smoking (if they smoke), and if appropriate, inhalers and tablets to make breathing easier and referral to pulmonary rehabilitation (a programme of exercise and education)⁸. Widespread evidence shows that the earlier the diagnosis, the quicker symptoms can be addressed and the better someone with COPD can maintain their quality of life. For treatments to be most effective, it's critical that people living with COPD are able to self-manage and monitor their own condition.

Missing millions

More than 1.3 million people in the UK have a diagnosis of COPD and it is estimated that at least a similar number of people have the condition but are as yet undiagnosed⁹. In the absence of treatment those without a diagnosis are at risk of deteriorating health and quality of life, with later diagnosis linked to higher levels of COPD exacerbations and a greater chance of dying from the disease¹⁰. The backlog of care as a result of the pandemic means that this group of undiagnosed people is growing, with a 51% reduction in COPD diagnoses in England alone in 2020 – equating to around 46,000 people¹¹.

A significant strain on health services with missed opportunities for treatment and care

While much of COPD diagnosis and care takes place in primary care settings, exacerbations can often lead to a hospital stay. At present COPD is estimated to cost the NHS £1.9 billion a year¹² and it is the second largest cause of emergency hospital admissions¹³. Since 2010, hospital admissions for lung disease have risen three times faster than admissions generally¹⁴.

When in hospital, the person with COPD should be under the care of a respiratory specialist. However, the National Asthma and COPD programme (NACAP) found 12.5% do not receive a review from a respiratory specialist at any time during their admission, and 33.3% do not receive this review within 24 hours of admission¹⁵. It is extremely important that COPD management is reviewed, including a review of medications, checking inhaler technique and the provision of an emergency rescue pack, and arrangements are made for a follow-up in primary care soon after discharge and for pulmonary rehabilitation to help the person to regain fitness. This will help to prevent further exacerbations and emergency hospital admissions. It has been found that is not always the case, with 24% not receiving appropriate discharge arrangements after admission¹⁶.

Chapter one

COPD diagnosis – delays and missed opportunities



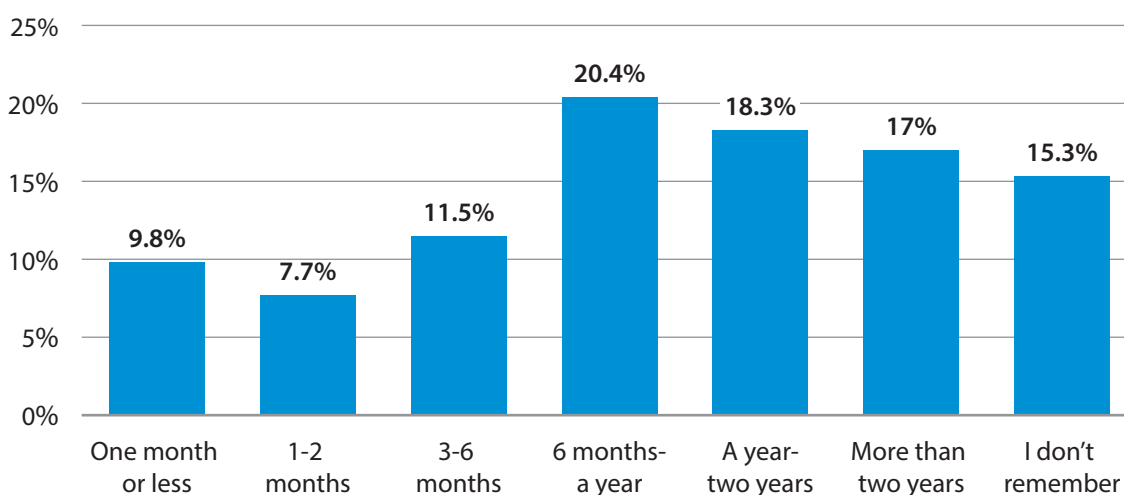
We asked respondents about the different stages of COPD care, from diagnosis through to receiving pulmonary rehabilitation and support to stop smoking. This section seeks to understand patient experiences of diagnosis, identifying the major barriers to timely diagnosis, and our recommendations for improving this.

Diagnosis of COPD needs to be faster and more accurate

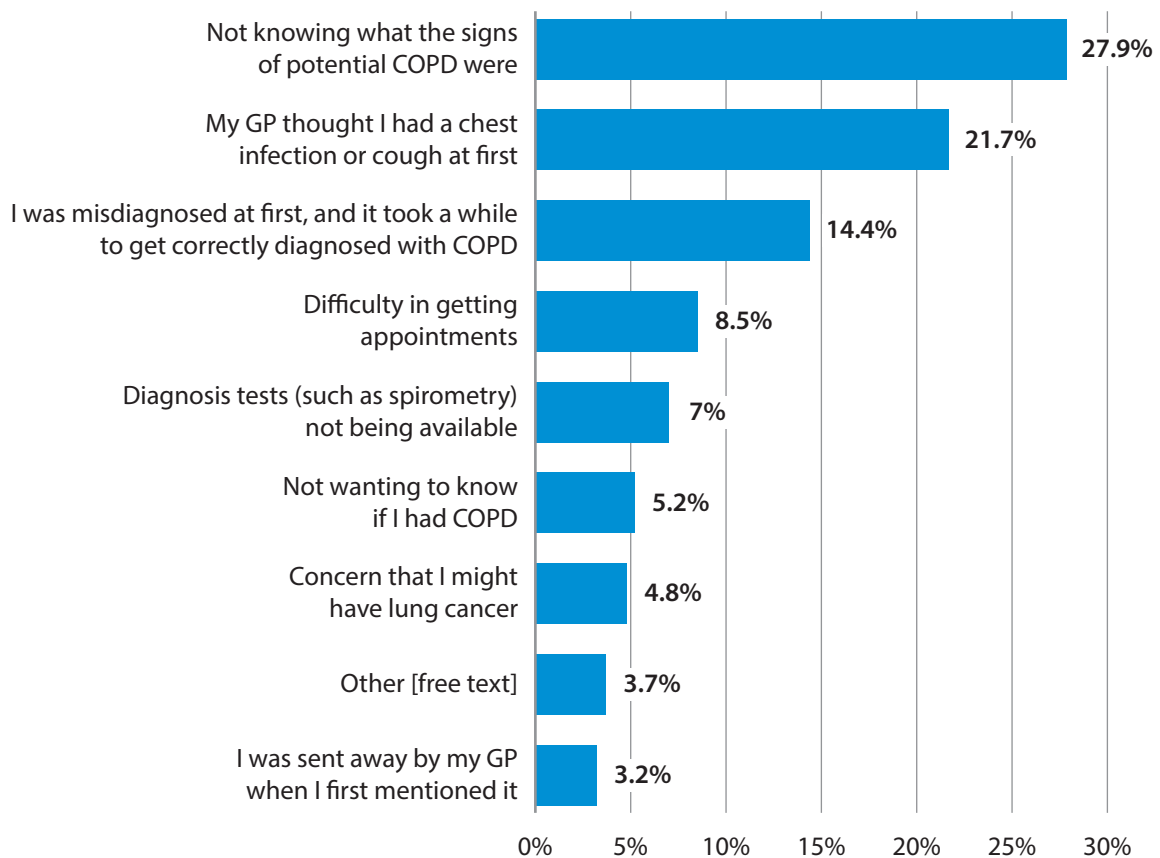
Getting a timely and accurate diagnosis of COPD is essential for accessing treatments and enabling people to live well with the condition. We know that later diagnosis is linked to higher levels of COPD exacerbations¹⁷. An early diagnosis means getting the right treatment earlier, helping slow this decline and enabling patients to manage their condition.

We found a range of issues are preventing people with COPD from receiving a quick and accurate diagnosis – only 29.1% of respondents experienced no delay. The first barrier is hesitation and reticence to talk about symptoms with a healthcare professional. Over a third of participants (35.3%) suffered from COPD symptoms for more than a year before talking about it, with only 1 in 10 (9.8%) discussing them within a month of onset (Figure 1).

Figure 1: How long did you experience symptoms before talking to a healthcare professional about it?



Once people did discuss their symptoms with a healthcare professional, most faced further barriers before a diagnosis was made. There are indications of sub-optimal responses to COPD symptoms by healthcare professionals, with 14.4% of respondents reporting an initial misdiagnosis, 21.7% having their symptoms mistaken for just a chest infection or cough, and 3.2% being sent away by their GP when they mentioned their symptoms.

Figure 2: What were the main barriers to getting a diagnosis?

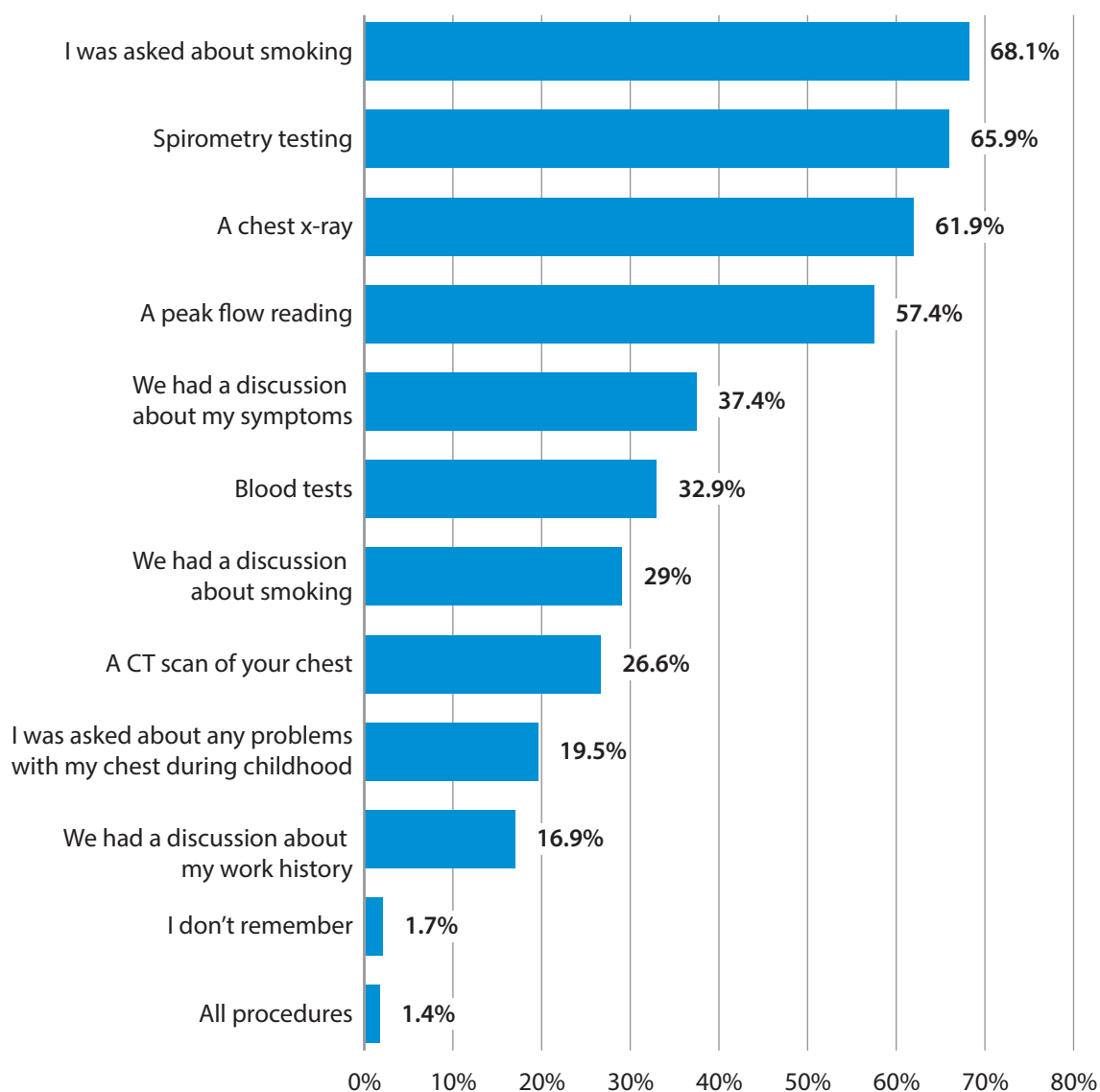
Too many are missing out on key diagnostic tests

COPD diagnosis depends on the use of spirometry (a test to measure how much and how quickly a person can exhale in one forced breath), which should be offered to anyone with the appropriate symptoms and history. Additional tests include chest imaging, blood tests to look for other potential causes of breathlessness symptoms and for the effect of COPD on the body. The diagnosis should be accompanied by a detailed conversation about symptoms, smoking and general health history and work¹⁸.

As Figure 3 shows, these diagnosis steps did not always take place*. Just under two thirds (65.9%) had spirometry testing to confirm their diagnosis, with only a third (32.9%) recalling blood tests. Discussions about health history were reported to focus on smoking, with only one in six (16.9%) having discussed their working history and potential links to their COPD. Only 1.4% recalled having all of the diagnosis elements performed.

* This data covers diagnoses over a long period (54.9% of respondents were diagnosed over five years ago), and care should be taken in applying this dataset to current practices in diagnosis.

Figure 3: Did any of the following take place during your diagnosis?



Almost half (49%) of respondents did not feel that they had enough support and knowledge to manage their COPD post diagnosis, and only 42.2% remembered receiving written support materials to support their new diagnosis. This is unacceptable situation; without this knowledge of the condition, self-management is much more difficult and exacerbations are more likely.

Policy recommendations

National and local health services across the UK must prioritise the urgent restart of spirometry testing in primary care for the diagnosis of COPD and other respiratory conditions. This should include adequate government funding and support so that there is capacity to conduct spirometry testing in primary care in all four nations.

Health services in all four nations should roll out national breathlessness pathways. In England, this has been under development for some time and now NHS England needs to roll it out quickly and comprehensively to improve the diagnosis of COPD and other respiratory conditions, as well as providing synergies with the diagnosis and management of cardiac conditions which commonly co-exist with COPD. Scotland, Wales and Northern Ireland should seek to develop similar diagnosis pathways based on learnings from this model.

National health services should amend guidance for GPs across the UK to ensure proactive case finding amongst high-risk groups to identify COPD and other lung conditions such as idiopathic pulmonary fibrosis and lung cancer in a timely way. In Scotland this could also be done by renewing the COPD Best Practice Guide published in 2017, while the Welsh Government should roll out a nationwide programme of lung screening, including spirometry, to the over-35 age group who currently smoke.

The diagnostic landscape in England is changing significantly at the moment, and so we have some specific recommendations here:

- **Questions on respiratory health should be made a mandatory part of the NHS Health Check,** to help identify the many undiagnosed cases of COPD. This should be supported by better compliance with NICE guidance on assessing patients presenting with COPD symptoms and referrals for spirometry where necessary.
- **Community Diagnostic Centres (CDCs) must be rolled out at the scale recommended in the Richards Review – 3 hubs per million people.** These need to be supported by multi-year investment from the Department of Health and Social Care and clearer guidelines from NHS England on how CDCs should operate, so that Primary Care Networks can get them up and running as soon as possible.
- **In the meantime, NHS England must ensure quality assured spirometry testing is being delivered in primary care.** People with COPD cannot afford to keep waiting for a formal diagnosis and see their symptoms and wellbeing deteriorate until CDCs are established. Unless spirometry and other diagnostic tests are restarted in general practice, the diagnostic backlog risks overwhelming CDCs as soon as they are established. While guidance has been published on how to conduct spirometry in a COVID-safe manner, this appears to have made little difference and there is a clear need for NHSE to intervene.
- **The NHS England Long Term Plan includes a commitment of £200,000 for training health care professionals involved in spirometry testing,** which has been put on hold indefinitely because of COVID-19. We want to see this unfrozen and used as soon as possible as part of the effort to address the significant backlog in respiratory care.

Chapter two

COPD care – low standards and huge variations



When we asked respondents about their experiences of COPD care, we found care levels to be generally substandard, with widespread variation across the UK. This section sets out our findings, and recommendations to ensure that every person with COPD is able to live as well as possible with it.

Failing on the five fundamentals

The National Institute of Health and Care Excellence (NICE) guidelines for COPD management¹⁹ set out five fundamentals of COPD care, which are:

- offer treatment and support to stop smoking
- offer pneumococcal and influenza vaccination
- offer pulmonary rehabilitation (PR) to those who score 3 or higher on the Medical Research Council (MRC) breathlessness scale²⁰
- co-develop a personalised self-management plan with the patient
- optimise treatment for co-morbidities – ensure that these are identified and then treated (at both diagnosis and each review)²¹.

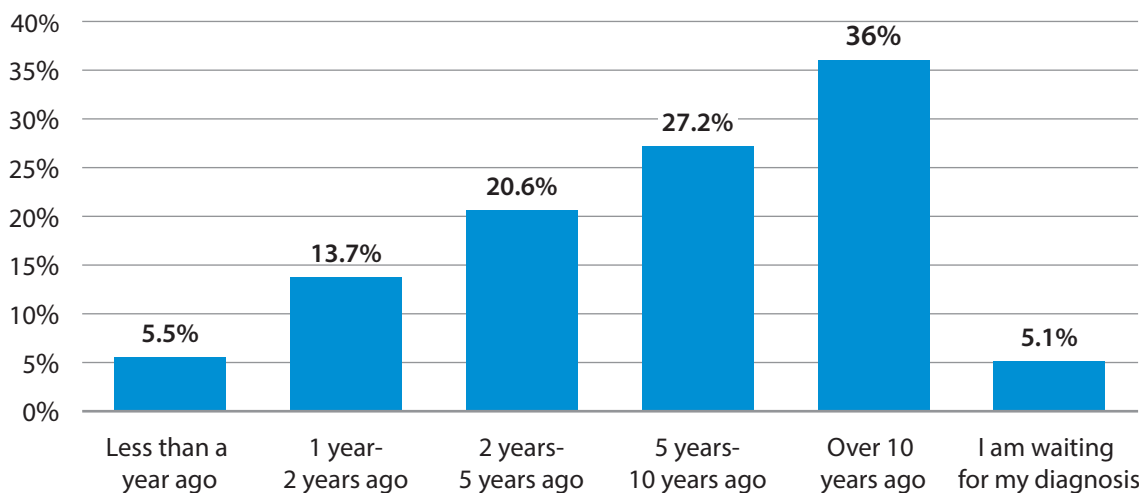
We asked all respondents whether they had received these five elements of COPD care. We only included the answers of those with a score of 3 and above on the MRC breathlessness scale about access to PR, and only those who were current smokers about whether smoking cessation support was offered.

Across the UK over three quarters (75.5%) of people with COPD are missing out on one or more of the five fundamentals of COPD care as recommended by NICE. This suggests that almost one million people with a COPD diagnosis (an estimated 905,000) are missing out on basic standards of high-value care, creating a huge burden for health services, as well as untold heartache for families around the country. This is an **alarmingly high number** and should be an urgent concern for policy makers across the UK, particularly in Scotland, Wales and Northern Ireland where the situation is even worse.

Patients are left to navigate their own way through the health system

There is a strong relationship between time since diagnosis and provision of care. Figure 4 shows 36% of those diagnosed more than ten years ago received all the elements of care they should get, compared to 5.5% of those diagnosed less than a year ago.

Figure 4: Provision of five fundamentals of care, and time since diagnosis



This indicates that familiarity and knowledge of living with COPD, as well as experience of navigating the healthcare system (and perhaps a strong relationship with healthcare professionals) are factors predictive of receiving higher levels of care and that perhaps patients are only likely to start getting the care they need when their condition has deteriorated.

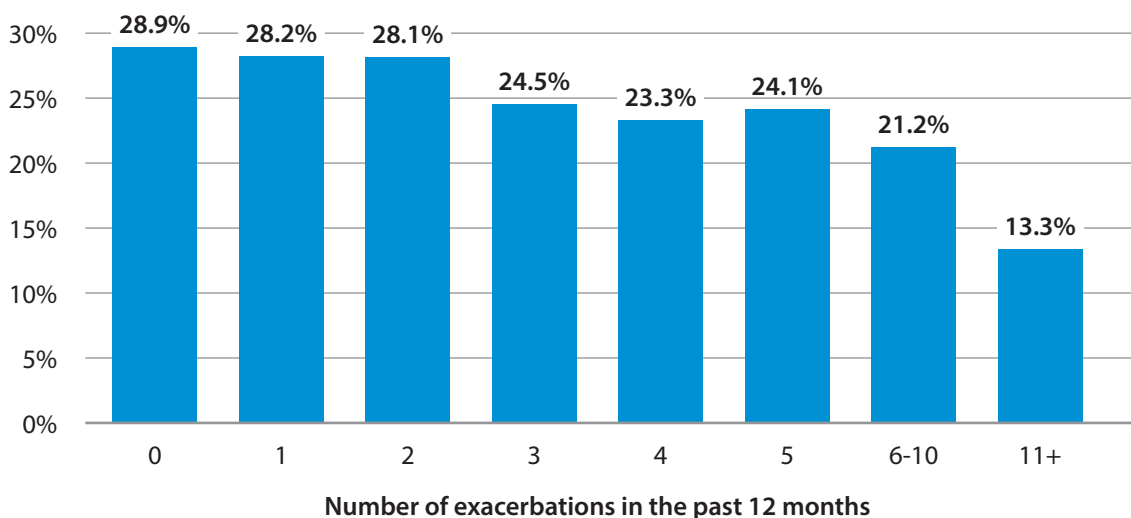
Better care is associated with fewer exacerbations

Figure 5 outlines the impact of not receiving basic levels of COPD care. People who had no COPD exacerbations[†] in the past 12 months received the highest level of basic COPD care (28.9%), whereas only 13.3% of people who had the most exacerbations (11 or more in the past 12 months) received all the elements of care, as outlined by NICE. Although there may be other factors influencing this relationship, patients with a higher rate of exacerbations were less likely to report receiving all elements of COPD care.

† An exacerbation (or flare-up) was defined in the survey question as suffering from some of these warning signs:

- Breathlessness gets worse, and this goes on for some time without getting better.
- Coughing more.
- Producing more sputum.
- A change in the colour and consistency of sputum.

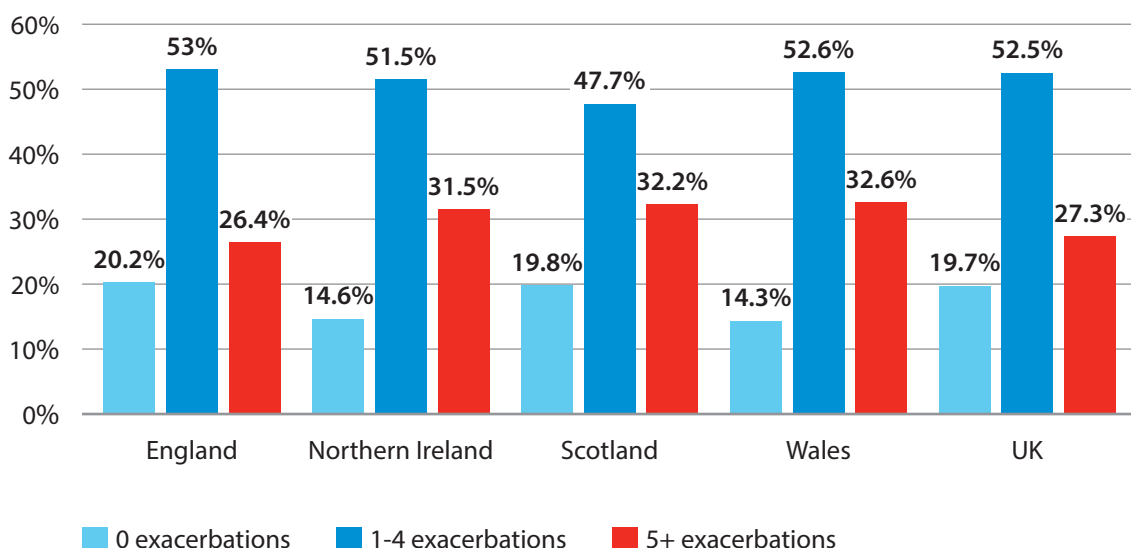
Figure 5: Percentage receiving the five fundamentals of COPD care, by number of exacerbations in the past 12 months



Knowing what to do in the event of an exacerbation is also extremely important, and this showed variation by level of care: 92.4% reporting that they had received all the five fundamentals of care told us they knew what to do, compared to 66.2% of those who did not receive this level of care.

This again illustrates the impact of not receiving the care laid out in clinical guidelines. Those who do not receive the recommended level of care face a greater risk of life-threatening exacerbations while feeling less equipped to deal with them. As Figure 6 shows, a higher proportion of people with COPD in Northern Ireland (32.6%), Scotland (32.2%) and Wales (32.6%) had five or more exacerbations in the previous year than in England (26.4%), where care provision is better.

Figure 6: Number of exacerbations in past year, by nation

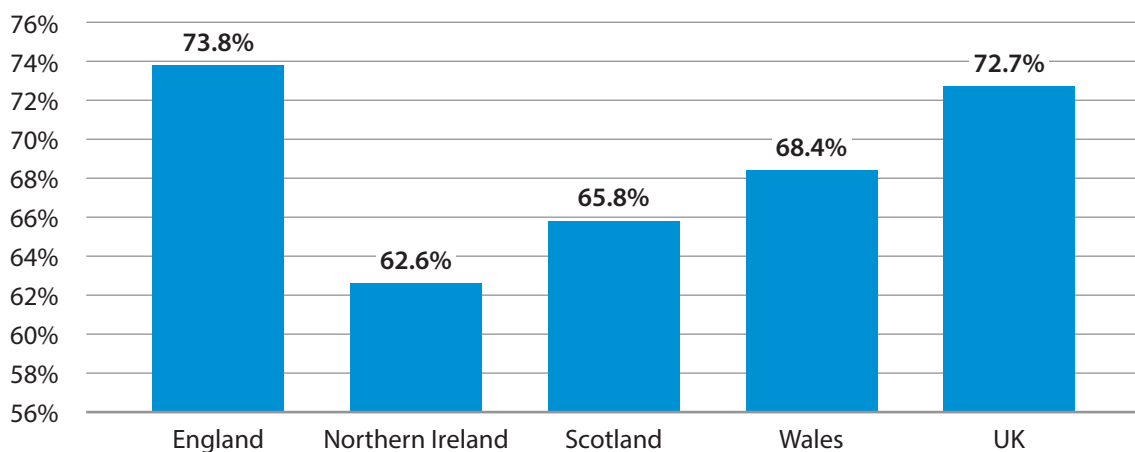


Not enough patients have self-management plans

One of the elements of the five fundamentals of care is the provision of a COPD self-management plan – there is evidence that these can improve quality of life and reduce hospitalisation²². Yet only 31.7% of respondents reported having a COPD self-management plan. Of those who do have a plan, only 60.4% told us that they had a say in its contents, thus not fully meeting the standard needed. Of those who did not have a COPD self-management plan, 42.4% told us they had not heard of them, with 61.3% not being offered one.

Provision of self-management plans was lower in Northern Ireland (30.2%), Scotland (24.5%) and Wales (23.2%) than in England (33.0%), and confidence in knowing what to do in the event of an exacerbation was lower in nations with lower levels of care provision. Given the fact that people with COPD in these nations are having more exacerbations, this is of particular concern. It means more people will end up in hospital due to their COPD.

Figure 7: Percentage knowing what to do in case of an exacerbation



An annual COPD review is an important opportunity to address many of the essential elements of COPD care. Only 62.9% percent had an annual review for their COPD in the past 12 months. Even with the disruption in care due to the COVID-19 pandemic, this is extremely low. Of those who had annual reviews for their COPD, 47.6% did so via videocall or over the phone, indicating that maintaining this appointment was still possible. With such a low provision of annual reviews, it is harder to provide the other elements of care[‡].

Pulmonary rehabilitation is vital and needs to be expanded

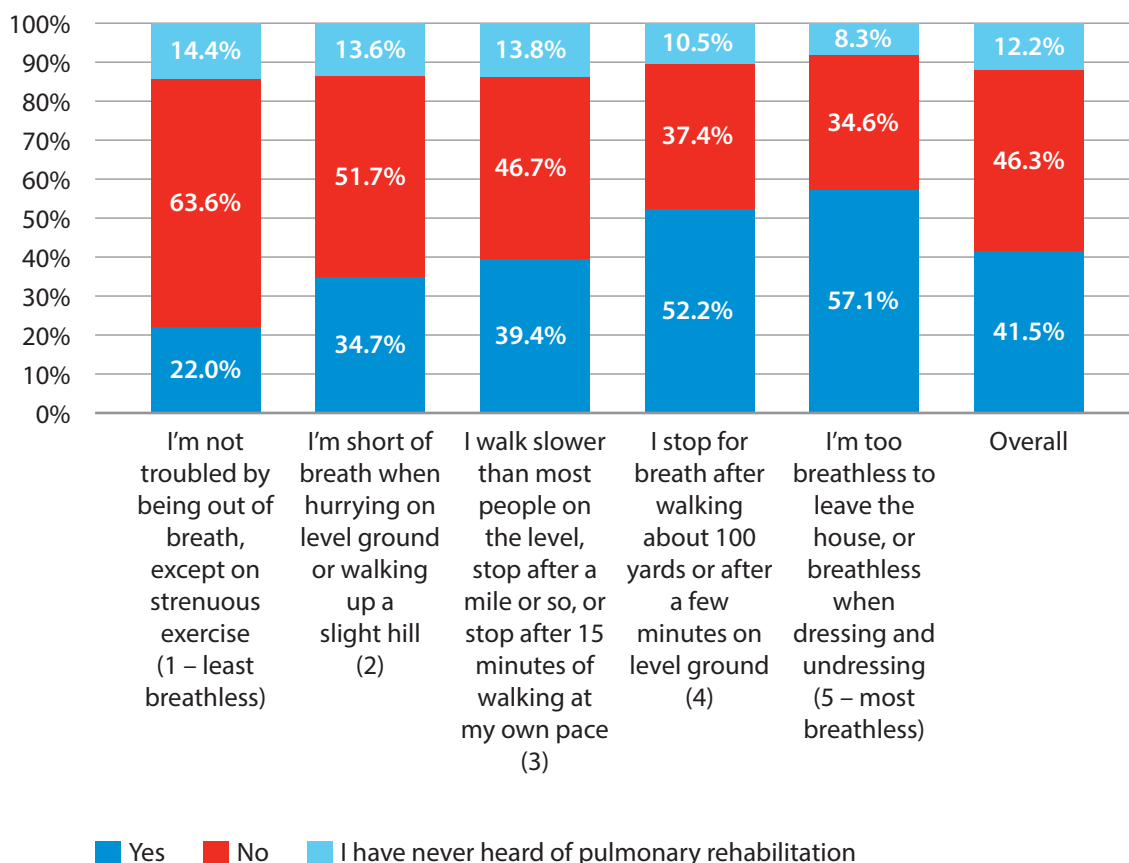
Access to PR for those at 3 or above on the MRC breathlessness scale²³ is one of the five fundamentals of care^{§24}. PR is an important part of treatment for COPD, and is essential in helping people manage their condition well. PR is a physical exercise and education programme, tailored to the individual's needs. It is delivered in a group setting by healthcare professionals including physiotherapists, nurses and occupational therapists²⁵ and can alleviate symptoms, help participants adjust to living with COPD and provide positive mental health impacts. It is also a chance to meet others living with COPD (and other lung conditions), therefore providing the opportunity for peer-to-peer support.

‡ The full results for all the elements of care in the five fundamentals are available in Appendix C.

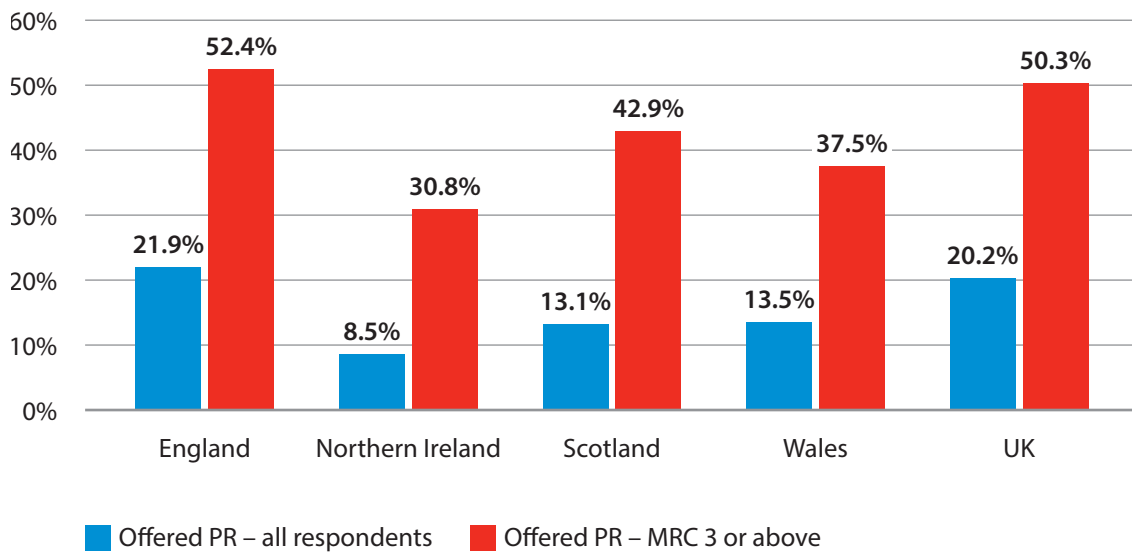
§ This is also now an indicator in the Quality and Outcomes Framework in England, which should increase access for eligible COPD patients to pulmonary rehabilitation. It is also likely to increase demand for PR courses.

Figure 8 shows the percentage of people with COPD at each level of the MRC breathlessness scale who have received PR as part of their care. Overall, 41.5% have attended a PR course, with this figure rising to 57.1% for those in category 5, the highest level. However, it is a concern that one in ten (10.7%) of those in MRC category 3 or above have never heard of PR. Despite the increasing use of PR in COPD care, there is still work to be done to raise its profile and ensure that it is promoted effectively and consistently to those who might benefit from it.

Figure 8: Percentages having PR as part of their care, by MRC breathlessness score



PR is a cornerstone of COPD care; people who participated in a course of PR generally reported its positive impact. Nearly half (48.5%) told us that doing a course of PR had improved their COPD symptoms, and 43.5% that it had improved their general fitness. Respondents were overwhelmingly positive in their experience of PR, with 82.6% telling us they would recommend it.

Figure 9: Percentage offered pulmonary rehabilitation who have not done it before, by nation

There is also significant variation in provision of PR across the UK, with only 8.5% of respondents who haven't had PR as part of their care in Northern Ireland being offered it – less than half the UK-wide figure of 20.2% (Figure 9). While the levels in England clearly require improvement, the level of unmet need for PR is particularly acute in Scotland, Wales and Northern Ireland, and needs particular attention.

Support to quit smoking: missed opportunities

While not all those diagnosed with COPD have a smoking history, most do and smoking is overall the biggest contributor to the development of the condition in the UK population. For people with COPD who still smoke at diagnosis, stopping smoking is the single most effective COPD treatment and the best thing they can do to improve their health, so they must be offered support to quit.

We found that 44% of those who smoked when diagnosed with COPD use this as an opportunity to quit tobacco. As shown in Figure 3, only two thirds of people with suspected COPD (68.1%) were asked about smoking on diagnosis with COPD. This means that many smokers, when diagnosed with COPD, are not asked about their smoking or encouraged to quit. This is despite this being one of the five fundamentals of COPD care as recommended by NICE, and essential in the prevention of other conditions such as cancer, heart disease and stroke, which have higher prevalence in people with COPD.

Policy recommendations

National health systems across the UK should ensure all five NICE recommended fundamentals of care are included as indicators in the Quality Outcomes Framework (QOF) for COPD. For instance, the current QOF for COPD in England only includes the offer of an influenza vaccination and PR at MRC grade 3 and above, while smoking cessation is included in the QOF elsewhere.

Local health services in all four nations must make it an urgent priority to restart any PR services that are yet still yet to resume. Where appropriate, face-to-face PR programmes should reopen, and national health systems must develop an evidence base on the delivery of digital PR and review current digital programmes to ensure high quality. This must be supported by additional investment to ensure services can meet increased demand for PR stemming from people with Long COVID-related breathlessness and those with pre-existing respiratory conditions who may have deconditioned throughout lockdowns.

National health systems in all UK nations must ensure PR services have capacity to treat all those who are currently eligible (MRC grade 3 or limited by breathlessness). Services should then look to expand access to PR to those with a breathlessness score of MRC grade 2 and above, so all those who could benefit from it have access to it. This will require sufficient funding from governments across the UK to ensure services have capacity to meet the increased need.

Health services in all parts of the UK must properly implement training in Very Brief Advice for Smoking Cessation across primary care and smoking cessation should be made a core part of undergraduate and postgraduate medical training, with a focus on delivery for those with respiratory conditions as well as incorporation into guidelines for the management of other long-term conditions. This would ensure that smokers who want to quit know that help is available. National public health agencies should monitor training levels and collect data on VBA use. Local health services should also ensure hospitals are delivering the “Ottawa Model” for smoking cessation to support people admitted to quit.

Chapter three

What does it mean to live with COPD?



When we asked people about the impact of COPD on their quality of life, we found that it has significant and far-reaching impacts that frequently stop people working, spending time with family, and pursuing their hobbies.

COPD affects people's life chances and choices from a relatively young age.

It is important to understand that COPD is not an illness that only affects older people; 21% of survey respondents were under 45 when they first started noticing COPD symptoms, and four in five (81.7%) were under 65. COPD reduces life choices and opportunities from a relatively young age.

Figure 10: Impact of COPD on social activities and employment

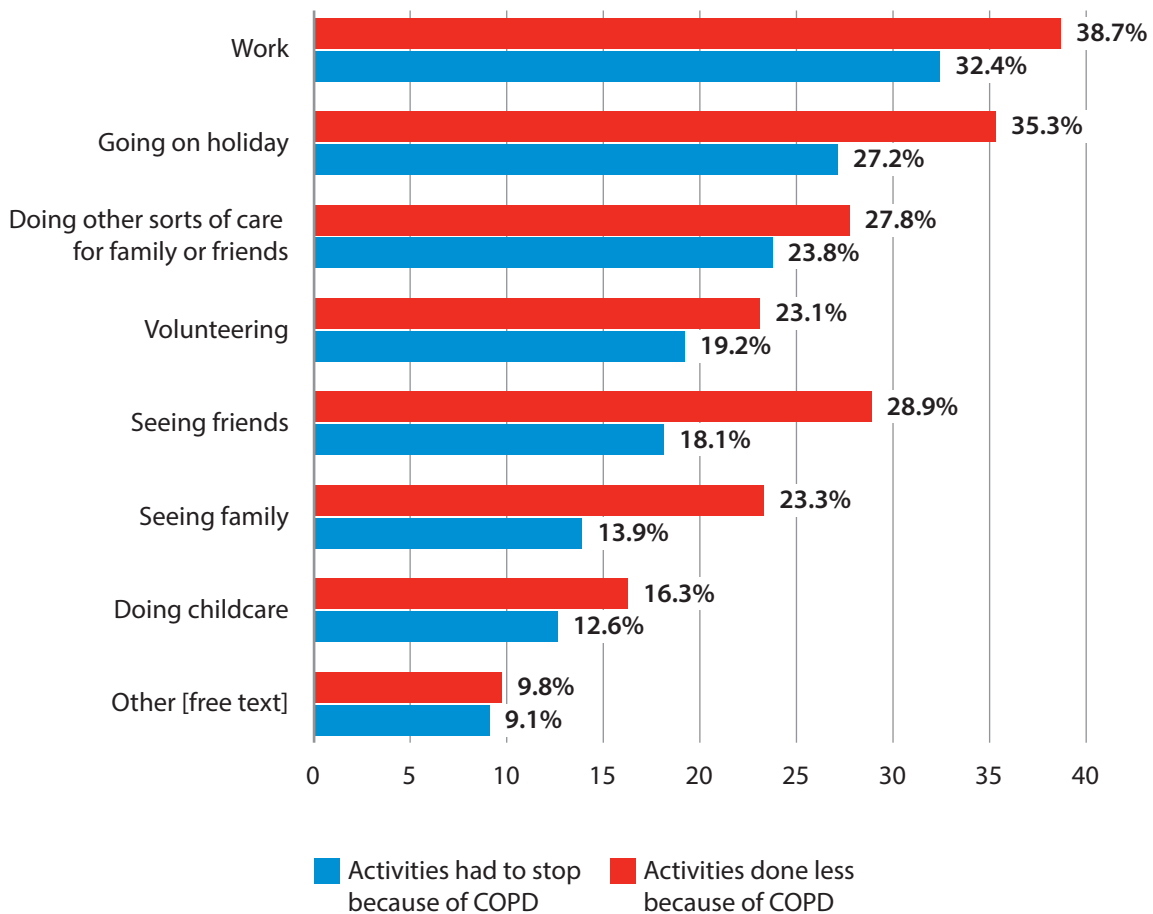
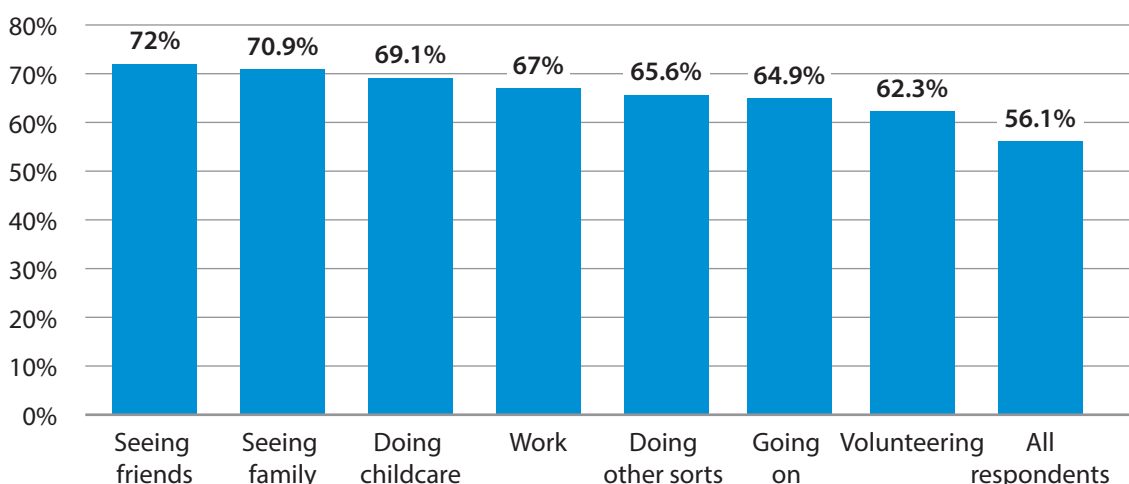


Figure 10 highlights the huge impact of COPD has on day-to-day life: 38.7% of respondents told us they had to work less, while 35.3% had to stop or reduce holidays. Seeing friends (28.9%) and seeing family (23.3%) also score highly.

COPD has wide-ranging impacts on people's mental health

Given this, it is not surprising that over half (56.1%) of respondents told us their mental health had worsened since receiving a COPD diagnosis (and 3.8% had been diagnosed with a new mental health condition since their COPD diagnosis). Within this, 72.0% of people who had to give up seeing friends completely reported worse mental health, while the figure was 70.9% for those who had to stop seeing their family.

Figure 11: Percentage who had to give up activities reporting a worsening of their mental health

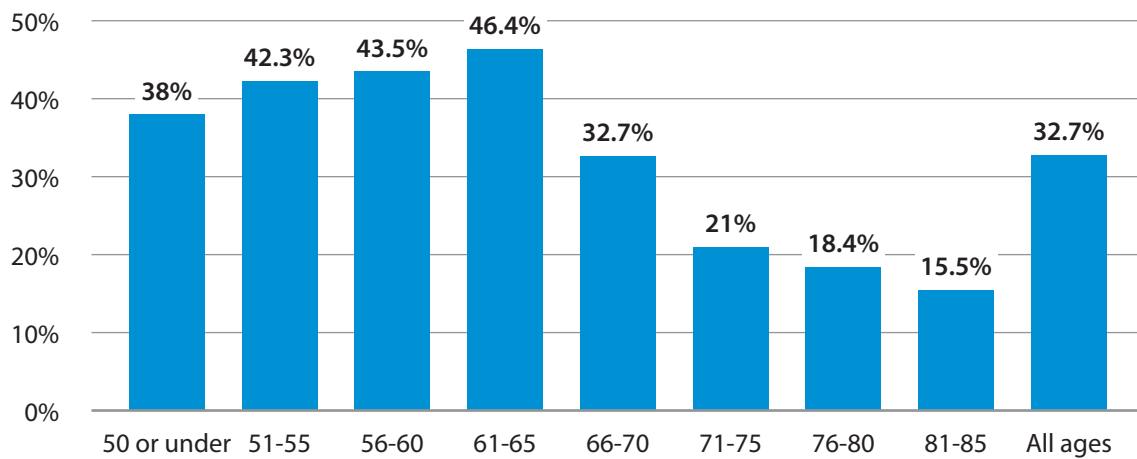


The mental health impacts of COPD are clearly profound and produce an additional burden for those suffering from this disease.

Around 420,000 people have their working lives cut short by COPD

We found that 38.0% of respondents under 50, and 43.9% of those 65 and under (below the UK state pension age) have had to give up work completely due to their COPD. Applying the overall figure of 32.4% of people with a current diagnosis of COPD having to give up work to the 1.3 million²⁶ people estimated to be living with COPD suggests that as many as 421,000 people in the UK may have had their working lives cut short by COPD.

This is a clear example of the wider impacts of COPD, pushing those who suffer from it out of the workplace and affecting the broader economy, as well as their own wellbeing. There is also evidence that having COPD increases absences from work, and "presenteeism" (attending work when not being well enough to perform)²⁷.

Figure 12: People with COPD who had to give up work, by age

While COPD can affect people with any working background, nearly half (49.4%) of people with COPD told us they had previously worked in a job where they had been exposed to dust, fumes or chemicals. When we asked those who had this previous exposure whether they had been given sufficient protective equipment to stay safe, only 19.2% said that they had. This resulted in 66.2% telling us they thought their job made their condition worse. This data on working history covers a range of years, but it shows there are workplace risk factors for COPD.

Chapter four



Perceptions of COPD – misunderstood and left behind

We already know that people in the poorest communities are two-and-a-half times more likely to develop COPD than those who are most affluent²⁸, and that disadvantages in early life also have a link to the development of COPD²⁹. There is a huge need to reduce health inequalities across society, and to address the very real discrimination that many people with COPD experience every day.

COPD does not affect all people equally

We explored the impact of employment history on diagnosis of COPD, asking about exposure to dust, fumes and chemicals, and poor-quality housing, issues potentially more likely to be experienced by those in lower-paid occupations. Over a quarter (25.9%) told us that their COPD was affected by where they live being cold and/or damp, and 42.9% told us that their COPD was affected by air pollution. Reducing air pollution will particularly benefit poorer people with COPD. Both poor air quality and housing quality disproportionately affect those living in the poorest communities.

COPD is misunderstood by the general public

We asked respondents to rate the knowledge of COPD among their family and friends, healthcare professionals, the media and the general public. As may be expected, healthcare professionals were rated as having the highest knowledge of COPD among these four groups, with two thirds (65.5%) rating their knowledge as “very good” or “good”. However, the media’s knowledge of COPD was rated as “poor” or “very poor” by 48.5% of people with COPD, while a majority (55.7%) also gave the general public this “poor” or “very poor” rating.

Sadly, this lack of knowledge often manifests as negative attitudes towards people with COPD; this has been described as “an unmet public health priority”³⁰, and our research bears this out. Nearly half (46.3%) of respondents thought there was a stigma attached to living with COPD while 27.9% told us they had faced direct stigma or discrimination since they were diagnosed with COPD.

Common problems reported by respondents include the perception that COPD is self-inflicted, due to the link to smoking, and that as an “unseen” condition it is harder for the others to understand. We also received many reports of discrimination in the workplace, and even stories about a lack of empathy and understanding from healthcare professionals.

Selected quotes from people with COPD on the stigma and discrimination they have faced

“ I tend to get a lot of shrugged shoulders when I say what is wrong with me. Previously employers have stated we have no idea what COPD is and don’t recognise it as a serious illness. I’ve received warnings for time off related to COPD. ”

[56-year-old man, Yorkshire and the Humber]

“ I went for a job interview and was told I wouldn’t be considered for the job because I couldn’t run up and down stairs if there was an emergency. ”

[65-year-old, East Midlands]

“ Nobody bothers with me because I can’t walk far, go shopping, dancing, drinking like them. ”

[64-year-old, North East]

“ People including healthcare professionals take it for granted that if you ever smoked you have caused the COPD yourself whether or not this is true and they make you feel guilty and that it is your own fault. ”

[60-year-old woman, South West]

“ Someone said I wouldn’t have it if I hadn’t smoked. It was a different era when I was young, everyone smoked. ”

[74-year-old woman, South East]

Other examples range from snide remarks or looks from members of the public to more overt discrimination in the workplace. These experiences underline the urgent need for greater public awareness of the realities of life with COPD, and for more understanding towards those living with the condition.

Policy recommendations

Governments and health services across the UK must ensure that addressing disparities in COPD prevalence, diagnosis and care are a major part of national health inequalities strategies, with concrete targets in place and clear plans for how to reach them.

We want to see public awareness campaigns run in England, Scotland, Wales and Northern Ireland, to improve understanding of lung conditions and when to seek medical advice for a long-term cough or breathlessness. This could be based upon the Taskforce for Lung Health’s “Take a Breath” campaign which was run in Birmingham this year, which aimed to connect people with their lungs and raise awareness of good lung health.

Concluding remarks

This report shows that people living with COPD are not getting the care they need, and it highlights the wide-ranging challenges they are face: from receiving a diagnosis, to accessing routine care, to knowing what to do in an exacerbation and living day-to-day with COPD. There are many improvements that need to be made to improve the lives, wellbeing and management of the condition. Fundamentally, we need to see a change in COPD care, and how COPD is perceived by wider society.

More than 1.3 million people in the UK have a diagnosis of COPD and it is estimated that at least a similar number of people have the condition but are as yet undiagnosed³¹, with the pandemic increasing this already large undiagnosed group. For a condition with a relatively high prevalence, and a significant impact on health services, COPD does not have the profile or prioritisation that it should. Given that people with COPD are also at a higher risk of having other long-term conditions, such as osteoporosis, diabetes and heart conditions, prioritisation is even more crucial and a more holistic approach is needed to diagnosis and monitoring.

COVID-19 has posed many challenges for our health services, and has created significant backlogs for many conditions, yet COPD was among the worst affected. This is especially concerning given that levels of diagnosis and care were already substandard and lagging far behind other conditions. This report highlights areas where people with COPD are being let down, and how care for COPD varies across the UK. All people with COPD in the UK should be able to access the care they are entitled to, and we will keep campaigning for improvements. We will be conducting another COPD survey next year and hope policy makers will put the recommendations in this report in place to improve the lives of people living with COPD across the UK.

About the survey

This survey was conducted by the British Lung Foundation between December 2020 and May 2021. The survey was conducted online, and responses were encouraged via both paid and organic social media, emails to our supporter base and promotion on the British Lung Foundation website. It is the first time a survey of this size has been conducted within the COPD population in the UK. After data cleaning (removing duplicate and incomplete responses), the survey received 8,232 responses. The majority of questions were not mandatory to answer, so may have different numbers of respondents. Survey questions are available in Appendix B, and tables of the data used in this report are in Appendix C.

This report was written by Andrew Cumella, Jon Foster and Jo McGowan.

The survey was written by and the analysis done by Andrew Cumella.

What people with COPD can do

If you have COPD – or know someone with COPD – there are some actions you can take to better understand your COPD (or suspected COPD), and to learn about the care you need:

- **Take the BLF Breath Test.** This asks you a series of questions about your breathing, making suggestions where needed. This is particularly important to take if you think you may have COPD (and perhaps haven't spoken to your GP), or your symptoms have been worsening recently.
- **Complete the BLF Patient Passport.** This will let you know whether you are getting the care you are entitled to – and need – to manage your COPD. It produces a report that you can discuss with your doctor or nurse.
- **Download a COPD self-management plan.** Using this will help you monitor your symptoms and better understand how to manage your COPD and when to get help.
- Get in touch with our nurse helpline for free, confidential advice on your COPD. You can call on 03000 030 555, or you can [send an email](#).
- Find out if there's a **BLF support group** in your area. These are groups run by volunteers where you can connect with others living with lung conditions, and better understand the experiences of others living with COPD and other lung conditions.
- Read our [webpages on COPD](#) to learn more about the condition.

Appendix A

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Appendix B

Survey questions

These are the questions asked in the survey to gain the data used in this report.

1. **What is your age?**
[respondent typed in numerical value]
2. **What nation do you live in?**
 - England
 - Northern Ireland
 - Scotland
 - Wales
3. [for respondents in England] **Which region do you live in?**
 - East Midlands
 - East of England
 - London
 - North East
 - North West
 - South East
 - South West
 - West Midlands
 - Yorkshire and Humber
4. **When were you diagnosed with COPD?**
 - In the last 6 months
 - 6 months – a year ago
 - 1 year – 2 years ago
 - 2 years – 5 years ago
 - 5 years – 10 years ago
 - Over 10 years ago
 - I am waiting for my diagnosis
5. **How long did you experience COPD symptoms before talking about it with your GP or another healthcare professional?**
Common symptoms include increasing breathlessness, a persistent chesty cough with phlegm that does not go away, frequent chest infections and persistent wheezing.
 - One month or less
 - 1–2 months
 - 3–6 months
 - 6 months – a year
 - A year – two years
 - More than two years
 - I don't remember
6. **How long did you have to wait between talking about your COPD symptoms with your GP or healthcare professional, to receiving a formal diagnosis?**
 - One month or less
 - 1–2 months
 - 3–6 months
 - 6 months – a year
 - A year – two years
 - More than two years
 - I don't remember

- 7. What were the main barriers to getting a diagnosis?**
- Difficulty in getting appointments
 - Diagnosis tests (such as spirometry) not being available
 - Not knowing what the signs of potential COPD were
 - Not wanting to know if I had COPD
 - I was misdiagnosed at first, and it took a while to get correctly diagnosed with COPD
 - I was sent away by my GP when I first mentioned it
 - My GP thought I had a chest infection or cough at first
 - I do not recall there being any barriers
 - Concern that I might have lung cancer
 - Other
- 8. Thinking about when you were diagnosed, did you have any of the following performed to confirm your diagnosis?**
- Spirometry testing
 - A peak flow reading
 - A chest x-ray
 - A CT scan
 - Blood tests
 - I was asked about smoking
 - We had a discussion about smoking
 - We had a discussion about my symptoms
 - We had a discussion about my work history
 - I don't remember
 - None of the above
- 9. After diagnosis, were you given any written materials to support your management of your COPD? This could include leaflets or links to the BLF website, for instance.**
- Yes
 - No
 - Don't remember
- 10. After your diagnosis, did you feel you had enough knowledge and support to manage your COPD?**
- Yes
 - No
 - Don't remember
- 11. Are you currently working?**
- Yes
 - No
- 12. Have you worked in a job where you were exposed to dust, fumes or chemicals? This may include working in a factory, using cleaning products or working in farming.**
- Yes
 - No
- 13. [if yes to above] In the job(s) where you were exposed to dust, fumes or chemicals, do you think that you had all the protective equipment that you needed to stay safe?**
- Yes
 - No
- 14. [if yes to working with dust etc] Do you think your job made your condition worse?**
- Yes
 - No

15. When do you get out of breath?

- I'm not troubled by being out of breath, except on strenuous exercise
- I'm short of breath when hurrying on level ground or walking up a slight hill
- I walk slower than most people on the level, stop after a mile or so, or stop after 15 minutes of walking at my own pace
- I stop for breath after walking about 100 yards or after a few minutes on level ground
- I'm too breathless to leave the house, or breathless when dressing and undressing

16. Have you had a planned review or planned check-up (sometimes called an annual review) of your COPD with your doctor or nurse in the last year?

- Yes – it was done face to face
- Yes – it was done over the phone / via videocall
- Yes – it was done via text
- No
- Not sure

17. Do you smoke?

- Yes
- I used to, but have given up
- I have never smoked

18. How old were you when you had your first cigarette?

[respondent typed in numerical value]

19. [for those who used to smoke] Did you give up smoking after being diagnosed with COPD?

- Yes
- No

20. [for those who smoke, or have smoked in past 12 months] In the past 12 months, have you been offered treatment and support to stop smoking?

- Yes
- No

21. [current smokers or used to] Since being diagnosed with COPD, have you tried to stop smoking?

- Yes
- No
- I wasn't smoking at the time I was diagnosed

22. What inspired you to quit smoking?

- Being diagnosed with COPD
- Other health reasons
- Stop Smoking campaigns (such as Stoptober)
- My family and/or friends
- Protecting others
- Saving money
- Other

23. In the past 12 months, have you had a flu jab?

- Yes
- No
- Don't know

24. Since diagnosis with COPD, have you had a pneumonia vaccine jab? This is also called the pneumococcal vaccine, or PPV.

- Yes
- No
- Don't know

25. Have you had pulmonary rehabilitation as part of your care?

Pulmonary rehabilitation (PR) is a programme of exercise and education designed for people living with COPD and other respiratory conditions

- Yes
- No

26. [if no to above] Have you ever been offered the chance to do pulmonary rehabilitation?

- Yes
- No

27. [if yes to PR] Has doing pulmonary rehabilitation improved your COPD symptoms?

- Yes
- No
- I don't know

28. [if yes to doing PR] Would you recommend pulmonary rehabilitation to others with COPD?

- Yes
- No
- I don't know

29. Do you currently have a COPD self-management plan?

- Yes
- No
- Don't know

30. [if yes to above] Did you have a chance to have a say about what was in the self-management plan? This could have been done via a conversation with your healthcare professional

- Yes
- No
- I can't remember

31. In the past 12 months, have you discussed any other long-term medical conditions that you have in relation to your COPD management with your doctor or nurse?

- Yes
- No
- Don't know
- I don't have any other long-term conditions

32. In the past 12 months, how many exacerbations or "flare-ups" of your COPD symptoms have you had?

By this, we mean you suffered from some of these warning signs:

- *Your breathlessness gets worse, and this goes on for some time without getting better*
- *You cough more*
- *You produce more sputum*
- *There's a change in the colour and consistency of your sputum*

[respondent typed in numerical value]

33. Do you know what to do if your COPD symptoms get worse (you have a flare-up)?

- Yes
- No

34. How would you rate the general public's understanding of what COPD is?

- Very good
- Good
- Average
- Poor
- Very poor

35. How would you rate the understanding of living with COPD from the following groups:

- Your friends and family
 - i. Very good
 - ii. Good
 - iii. Average
 - iv. Poor
 - v. Very poor

- Healthcare professionals
 - i. Very good
 - ii. Good
 - iii. Average
 - iv. Poor
 - v. Very poor

- The general public
 - i. Very good
 - ii. Good
 - iii. Average
 - iv. Poor
 - v. Very poor

- The media
 - i. Very good
 - ii. Good
 - iii. Average
 - iv. Poor
 - v. Very poor

36. What activities have you had to do less of because of your COPD? [multiple choice]

- Work
- Seeing friends
- Seeing family
- Volunteering
- Doing childcare
- Doing other sorts of care for other family or friends
- Going on holiday
- Other [free text]

37. What activities have you had to stop doing because of your COPD? [multiple choice]

- Work
- Seeing friends
- Seeing family
- Volunteering
- Doing childcare
- Doing other sorts of care for other family or friends
- Going on holiday
- Other [free text]

38. Is your COPD affected because where you live is:

- Cold?
- Damp?
- Both cold and damp?

39. Have you ever felt that there is a stigma attached to living with COPD?

- Yes
- No
- Don't know

40. Do you feel you have faced any stigma or discrimination due to having COPD?

- Yes
- No

41. [if yes to above] **Can you describe what took place?**

[free text]

42. **How has being diagnosed with and living with COPD impacted upon your mental health?**

- It has had no impact
- It has made it much better
- It has made it a bit better
- It has made it a bit worse
- It has made it much worse

43. **Which of the following applies to care for your mental health since you were diagnosed with COPD?** [multiple choice]

- I have spoken to my family and/or friends about it
- I have spoken to my GP about it
- I have been diagnosed with a new mental health condition
- I have received a new prescription for my mental health
- I have been referred to a specialist for mental health treatment
- I have not needed mental health care
- Other

Appendix C

Data tables

Table 1: How long did you experience COPD symptoms before speaking to a healthcare professional about it?

Time waited	Respondents	Percentage
One month or less	797	9.8%
1-2 months	621	7.7%
3-6 months	934	11.5%
6 months – a year	1652	20.4%
A year – two years	1483	18.3%
More than two years	1377	17.0%
I don't remember	1238	15.3%
Overall	8102	

Table 2: What were the main barriers to getting a diagnosis?

Barrier	Respondents	Percentage
I was sent away by my GP when I first mentioned it	257	3.2%
Other [free text]	297	3.7%
Concern that I might have lung cancer	387	4.8%
Not wanting to know if I had COPD	415	5.2%
Diagnosis tests (such as spirometry) not being available	565	7.0%
Difficulty in getting appointments	684	8.5%
I was misdiagnosed at first, and it took a while to get correctly diagnoses with COPD	1152	14.4%
My GP thought I had a chest infection or cough at first	1744	21.7%
Not knowing what the signs of potential COPD were	2242	27.9%
I do not recall there being any barriers	2338	29.1%
Total	8023	

Table 3: Did any of the following take place during your diagnosis?

Test	Respondents	Percentage
None of the above	102	1.3%
All procedures	113	1.4%
I don't remember	137	1.7%
We had a discussion about my work history	1345	16.9%
I was asked about any problems with my chest during childhood	1549	19.5%
A CT scan of your chest	2116	26.6%
We had a discussion about smoking	2305	29.0%
Blood tests	2616	32.9%
We had a discussion about my symptoms	2969	37.4%
A peak flow reading	4558	57.4%
A chest x-ray	4921	61.9%
Spirometry testing	5234	65.9%
I was asked about smoking	5408	68.1%

Table 4: Respondents feeling they had enough knowledge and support after diagnosis to manage their condition

Response	Respondents	Percentage
Yes	3088	39.4%
No	3842	49.0%
Don't know	903	11.5%
Total	7833	

Table 5: Respondents being given written material to support them after diagnosis

Response	Respondents	Percentage
Yes	3333	42.2%
No	3546	44.9%
Don't remember	1019	12.9%
Grand Total	7898	

Table 6: Provision of the Five Fundamentals of COPD care, and time since COPD diagnosis

Time since diagnosis	Number of respondents			Percentage	
	Received 5F	Did not receive 5f	All respondents	Received 5F	Did not receive 5f
Less than a year ago	27	467	494	5.5%	94.5%
1 year – 2 years ago	112	705	817	13.7%	86.3%
2 years – 5 years ago	442	1708	2150	20.6%	79.4%
5 years – 10 years ago	626	1676	2302	27.2%	72.8%
Over 10 years ago	774	1374	2148	36.0%	64.0%
I am waiting for my diagnosis	10	188	198	5.1%	94.9%
Overall	1991	6118	8109	24.6%	75.4%

Table 7: Provision of the Five Fundamentals of COPD care, and number of exacerbations in the past 12 months

Number of exacerbations in the past 12 months	Received	Not received	All respondents	Received	Not received
0	441	1084	1525	28.9%	71.1%
1	308	783	1091	28.2%	71.8%
2	345	883	1228	28.1%	71.9%
3	240	741	981	24.5%	75.5%
4	173	570	743	23.3%	76.7%
5	101	318	419	24.1%	75.9%
6-10	199	740	939	21.2%	78.8%
11+	99	643	742	13.3%	86.7%

Table 8: Provision of the Five Fundamentals of COPD care, and knowing what to do in the event of an exacerbation

Know what to do with an exacerbation	Respondents			Percentages		
	Received 5F	Not received 5F	All respondents	Received 5F	Not received 5F	All respondents
Yes	1824	4003	5827	92.4%	66.2%	72.7%
No	151	2042	2193	7.6%	33.8%	27.3%
Overall	1975	6045	8020	100.0%	100.0%	100.0%

Table 9: Number of exacerbations in past year, by nation

	Number of exacerbations	England	Northern Ireland	Scotland	Wales	UK
Respondents	0 exacerbations	1301	19	121	62	1503
	1-4 exacerbations	3411	67	292	229	3999
	5+ exacerbations	1697	41	197	142	2077
	Outliers	30	3	2	2	37
Percentages	0 exacerbations	20.2%	14.6%	19.8%	14.3%	19.7%
	1-4 exacerbations	53.0%	51.5%	47.7%	52.6%	52.5%
	5+ exacerbations	26.4%	31.5%	32.2%	32.6%	27.3%
	Outliers	0.5%	2.3%	0.3%	0.5%	0.5%

Table 10: Respondents who smoke offered support to quit smoking in the past 12 months, by nation

	England	Northern Ireland	Scotland	Wales	No nation listed	UK
Yes	612	19	62	54	7	754
No	481	13	77	29	6	606
Overall	1093	32	139	83	13	1360
Yes	56.0%	59.4%	44.6%	65.1%	53.8%	55.4%
No	44.0%	40.6%	55.4%	34.9%	46.2%	44.6%

Table 11: Respondents who have had both flu and pneumococcal jabs, by nation

	England	Northern Ireland	Scotland	Wales	No nation listed	UK
Had both flu and pneumococcal jabs	4516	68	364	279	52	5279
All respondents	6813	141	652	459	167	8232
Percentage	66.3%	48.2%	55.8%	60.8%	31.1%	64.1%

Table 12: Respondents who have been offered – or have had – pulmonary rehabilitation and are 3 or above on the MRC breathlessness scale

Had PR/were offered it	England	Northern Ireland	Scotland	Wales	(blank)	UK
Respondents	2154	24	184	114	21	2497
Total respondents	3399	65	359	240	41	4104
Percentage	37.2%	47.7%	44.0%	49.2%	41.5%	38.7%

Table 13: Respondents who have a self-management plan

	England	Northern Ireland	Scotland	Wales	UK
Yes	2228	42	159	106	2535
No	3720	83	431	306	4540
I don't know	811	14	60	45	930
Total respondents	6759	139	650	457	8005
Yes	33.0%	30.2%	24.5%	23.2%	31.7%
No	55.0%	59.7%	66.3%	67.0%	56.7%
I don't know	12.0%	10.1%	9.2%	9.8%	11.6%

Table 14: Respondents who have a self-management plan that they co-developed with a healthcare professional

	England	Northern Ireland	Scotland	Wales	UK
Yes	1345	16	98	65	1540
No	441	15	29	25	512
I can't remember	434	11	32	16	499
All respondents	6759	139	650	457	8005
Yes	19.9%	11.5%	15.1%	14.2%	19.2%
No	6.5%	10.8%	4.5%	5.5%	6.4%
I can't remember	6.4%	7.9%	4.9%	3.5%	6.2%

Table 15: Respondents who were asked about any other long term condition

	England	Northern Ireland	Scotland	Wales	UK
Yes	2068	40	189	130	2427
No	3738	83	381	273	4475
I don't have any other long term medical conditions	645	7	52	35	739
Don't know	331	8	26	18	383
Overall	6782	138	648	456	8024
Yes	30.5%	29.0%	29.2%	28.5%	30.2%
No	55.1%	60.1%	58.8%	59.9%	55.8%
I don't have any other long term medical conditions	9.5%	5.1%	8.0%	7.7%	9.2%
Don't know	4.9%	5.8%	4.0%	3.9%	4.8%

Table 16: Respondents knowing what to do in an exacerbation, by nation

Knowing what to do	England	Northern Ireland	Scotland	Wales	UK
Yes	4949	87	423	307	5766
No	1754	52	220	142	2168
Overall	6703	139	643	449	7934
Yes	73.8%	62.6%	65.8%	68.4%	72.7%
No	26.2%	37.4%	34.2%	31.6%	27.3%

Table 17: Respondents having an annual review of their COPD

Annual review?	Respondents	Percentage
Yes – it was done via text	76	0.9%
Yes – it was done over the phone/via videocall	2430	29.9%
Yes – it was done face to face	2600	32.0%
No	2792	34.4%
Not sure	221	2.7%
Overall	8119	

Table 18: Having pulmonary rehabilitation (PR) as part of care, by MRC breathlessness scale score

	I'm not troubled by being out of breath, except on strenuous exercise (1 – least breathless)	I'm short of breath when hurrying on level ground or walking up a slight hill (2)	I walk slower than most people on the level, stop after a mile or so, or stop after 15 minutes of walking at my own pace (3)	I stop for breath after walking about 100 yards or after a few minutes on level ground (4)	I'm too breathless to leave the house, or breathless when dressing and undressing (5 – most breathless)	Overall
Yes	163	1111	413	1011	639	3337
No	471	1658	489	724	387	3729
I have never heard of pulmonary rehabilitation	107	435	145	203	93	983
Overall	741	3204	1047	1938	1119	8049
Yes	22.0%	34.7%	39.4%	52.2%	57.1%	41.5%
No	63.6%	51.7%	46.7%	37.4%	34.6%	46.3%
I have never heard of pulmonary rehabilitation	14.4%	13.6%	13.8%	10.5%	8.3%	12.2%

Table 19: Inspiration behind quitting smoking

Response	Respondents	Percentage
Being diagnosed with COPD	2950	44.0%
Other health reasons	1982	29.5%
Stop smoking campaigns (such as Stoptober)	210	3.1%
My family and/or friends	1738	25.9%
Protecting other people	547	8.2%
Saving money	1252	18.7%
Other [free text]	672	10.0%
	6708	

Table 20: Activities limited or stopped because of COPD

Activity	Respondents	Activities done less of because of COPD	Respondents	Activities had to stop because of COPD
Other [free text]	804	9.8%	751	9.1%
Doing childcare	1340	16.3%	1040	12.6%
Volunteering	1904	23.1%	1581	19.2%
Seeing family	1921	23.3%	1145	13.9%
Doing other sorts of care for family or friends	2285	27.8%	1957	23.8%
Seeing friends	2378	28.9%	1494	18.1%
Going on holiday	2909	35.3%	2235	27.2%
Work	3185	38.7%	2671	32.4%
All respondents	8232		8232	

Table 21: Impact of COPD diagnosis on the mental health of respondents

Impact of COPD diagnosis on mental health	Respondents	Percentage
It has made it much better	172	2.1%
It has made it a bit better	446	5.5%
It has had no impact	2924	36.2%
It has made it a bit worse	3189	39.5%
It has made it much worse	1343	16.6%
Overall	8074	

Table 22: Respondents who had to give up activities due to their COPD reporting that their mental health got worse

Activity	Respondents whose mental health got worse and gave up these activities	All respondents who gave up these activities	Percentage had to give up whose mental health got worse
Seeing friends	1065	1479	72.0%
Seeing family	802	1132	70.9%
Doing childcare	706	1022	69.1%
Work	1774	2646	67.0%
Doing other sorts of care for family or friends	1266	1929	65.6%
Going on holiday	1433	2208	64.9%
Volunteering	971	1559	62.3%
All respondents	4532	8074	56.1%

Table 23: Respondents who gave up work due to their COPD

	50 or under	51-55	56-60	61-65	66-70	71-75	76-80	81-85	All ages
Gave up work	155	248	439	673	558	347	163	46	2629
Did not give up work	253	338	570	778	1147	1306	723	250	5365
Percentage of age group who gave up work	38.0%	42.3%	43.5%	46.4%	32.7%	21.0%	18.4%	15.5%	32.7%

Table 24: Respondents having the correct protective equipment in jobs they were exposed to dust, fumes and/or chemicals

	Respondents	Percentage
Yes	4009	49.4%
No	4099	50.6%
Overall	8108	

Table 25: Respondents having the correct protective equipment in jobs they were exposed to dust, fumes and/or chemicals

	Respondents	Percentage
Yes	763	19.2%
No	3213	80.8%
Overall	3976	

Table 26: Respondents opinion on whether their job made their COPD worse

	Respondents	Percentage
Yes	2625	66.3%
No	1337	33.7%
Overall	3962	

Table 27: Respondents COPD affected by their housing

	Respondents	Percentage
Cold housing	655	8.1%
Damp housing	315	3.9%
Both cold and damp housing	1119	13.9%
My COPD is not affected by where I live	5970	74.1%
Grand Total	8059	

Table 28: COPD affected by air pollution

	Respondents	Percentage
Yes – often	979	12.1%
Yes – sometimes	2445	30.2%
No	2476	30.6%
Don't know	2185	27.0%
Grand Total	8085	

Table 29: Rating of healthcare professionals' understanding of COPD

Rating	Respondents	Percentage
Very good	2212	27.3%
Good	3097	38.2%
Average	2186	27.0%
Poor	514	6.3%
Very poor	99	1.2%
Grand Total	8108	

Table 30: Rating the media's understanding of COPD

Rating	Respondents	Percentage
Very good	80	1.0%
Good	645	8.0%
Average	3436	42.5%
Poor	3129	38.7%
Very poor	792	9.8%
Grand Total	8082	

Table 31: Rating of the general public's understanding of COPD

Rating	Respondents	Percentage
Very good	46	0.6%
Good	298	3.7%
Average	2584	31.9%
Poor	4135	51.1%
Very poor	1031	12.7%
Grand Total	8094	

Table 32: Respondents thoughts on whether there is a stigma attached to living with COPD

Rating	Respondents	Percentage
Yes	3757	46.3%
No	2719	33.5%
Don't know	1632	20.1%
Grand Total	8108	

Table 33: Respondents facing stigma or discrimination due to their COPD

Rating	Respondents	Percentage
Yes	2265	27.9%
No	4430	54.6%
Don't know	1419	17.5%
Grand Total	8114	

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