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COPD

IN THE UK

Delayed diagnosis and unequal care

Delayed diagnosis and unequal care: The reality for people with chronic obstructive pulmonary disease (COPD) in the UK in 2022.

November 2022

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Foreword

This report outlines the findings of our second annual survey of people with chronic obstructive pulmonary disease (COPD) in the UK. It provides key insights into the experience of people with this lung condition in 2021–22. The survey reveals a worrying picture of delayed diagnosis, substandard care, and a disproportionate impact of inequalities on people with COPD.

New COPD diagnoses fell by 51% as a result of the pandemic.¹ At the end of 2022, there are still barriers to the restart of crucial diagnostic services, such as quality assured spirometry tests. This will impact many people who are waiting for an accurate diagnosis. We want to see an urgent increase in the availability of spirometry across the system, to at least pre-pandemic levels. Central support for solutions to achieving this is required across the UK.

Our survey shows a quarter of people are waiting five years or more for a diagnosis, and that diagnostic delays have worsened since last year. This is likely to have the biggest impact on the poorest communities, who also tend to face the greatest health challenges.

Diagnosis of COPD needs to be faster and more accurate. To achieve this, we are calling for a pre-diagnosis breathlessness pathway Diagnostic Pathway Support Toolⁱ to be rolled out in every UK nation.

We want to see a public awareness campaign in every UK nation to encourage people with key symptoms, such as breathlessness, to seek advice so that they can benefit from being diagnosed and treated.

Our survey found that even once a diagnosis of COPD has been made, people struggle to get the basic care they need. NICE has defined the “five fundamentals of COPD care”: smoking cessation, vaccination, pulmonary rehabilitation, personalised self-management planning, and optimising treatment for co-morbidities.² The proportion of people with COPD surveyed that had received all five fundamentals has fallen from 24.5% to just 17.6%, a reduction of 6.9%.

Social inequalities contribute to the development of COPD and impact the quality of care that poorer people with COPD receive.³ This injustice cannot be allowed to continue. At Asthma + Lung UK we will demand better care for people with COPD, especially those disproportionately impacted by health inequalities.

We hope to see the prioritisation of lung health in all inequalities and national health strategies, to help prevent lung conditions and ensure that all people with COPD get the timely diagnosis and quality care that they deserve.



Sarah Woolnough
Chief Executive, Asthma + Lung UK



ⁱ Like the one for adults presenting with chronic persistent breathlessness of more than 8 weeks’ duration, which has been developed in England. This has been published on the FutureNHS platform, which is accessible to anyone working in health and social care via: www.england.nhs.uk/futurenhs-platform.

Executive summary

Chronic obstructive pulmonary disease (COPD) is the name for a group of lung conditions which make it more difficult to breathe air out of the lungs, due to a permanent narrowing of the airways and destruction of lung tissue. COPD includes long-term (chronic) bronchitis and emphysema. In the UK there are 1.4 million people with a diagnosis of COPD. Each year around 30,000 people in the UK die from COPD. In terms of diagnosed cases, this makes COPD the second most common lung disease in the UK, after asthma.⁴ Around 2% of the whole population (4.5% of all people aged over 40) live with diagnosed COPD.⁵

Asthma + Lung UK has gathered evidence⁶ of patient experiences of COPD care through our COPD Patient Passport, a checklist for people with COPD to ensure they are receiving the best care.⁷ Building on this and our 2021 survey, Asthma + Lung UK conducted this survey of over 6,500 people with COPD between January 2022 and April 2022.

One year on from our first report in 2021,⁸ significant issues with delays to diagnosis and the quality of COPD care identified then have not been resolved and, in many cases, have deteriorated. Our survey also highlights the disproportionate impact of inequalities on people with COPD.

Delays to diagnosis

- Even before the COVID-19 pandemic there were already problems with diagnosis and care for people with COPD. Available estimates of the proportion of people with COPD who are undiagnosed vary between about half⁹ to as much as two thirds.¹⁰ Available evidence from NICE published in 2011, and updated in 2016, indicates that there could be as many as two million people in the UK with undiagnosed, and therefore untreated, COPD.¹¹ More research is needed to update these figures.
- Shockingly, **12.4% of respondents (one in eight) waited more than 10 years for a diagnosis.**
- **Almost a quarter of people (nearly one in four) surveyed are waiting five years or more for a diagnosis.**
- More than a third (34%) of people surveyed said they were unable to recognise the signs of COPD, and around 1 in 4 (23%) said they were misdiagnosed as their doctor thought they had a chest infection or cough.
- Other key problems included access to care, with 1 in 4 (26%) people saying they couldn't get an appointment and 1 in 5 (21%) being unable to access key tests, such as spirometry, which are essential for an accurate diagnosis.

Quality of care

Five fundamentals of COPD care:

- Offer treatment and support to **stop smoking**
- Offer **pneumococcal (pneumonia) and influenza vaccinations**
- Offer **pulmonary rehabilitation** if indicated
- Co-develop a personalised **self-management plan**
- Optimise treatment for **co-morbidities**
- Treatments and plans should also be revisited at every review.¹²

It is clear from our 2022 survey that care for people with COPD has not yet returned even to pre-pandemic levels. Our results demonstrate the impact of COVID-19 on the care of people with lung conditions:

- **Only 21.6% had received spirometry in the last 12 months**, despite guidance published in April 2021 (a year before our survey closed) indicating that spirometry is safe.¹³
- **UK-wide, those that had received the full package of care (all five fundamentals¹⁴ outlined above) has dropped from 24.5% to just 17.6%, a reduction of 6.9%.**
- **This means less than a fifth of people with COPD surveyed received recommended levels of care.**
- **Overall levels of five fundamentals (5F) care provision have dropped in every nation**, most prominently in England (**from 26% in 2021 to 18.4% in 2022**).
- Our survey also shows drops in several of the individual fundamentals, including smoking cessation services (down 1.1%), provision of key vaccines (0.7% for flu and 2.3% for pneumococcal (pneumonia) vaccines), and pulmonary rehabilitation (PR) (down 4.2%ⁱⁱ), as well as the number of people who have co-developed their personalised self-management plan (down 2.4%)ⁱⁱⁱ.

This is a shocking and disappointing result, especially considering that people with COPD are at increased risk from COVID-19, and as such, are amongst those who should have been prioritised to ensure their condition was well managed and controlled as far as possible through the pandemic.

We know that those that receive the five fundamentals of care have better outcomes, such as fewer exacerbations and improved self-management.¹⁵ There is also a related impact on NHS resources: providing good basic care to people with COPD may prevent hospital admissions later, saving the NHS money in the long term.

This survey demonstrates the challenging circumstances facing people with COPD this year, such as the backlog for care and the pressures on the NHS.

Impact of health disparities

Poorer people are more likely to develop COPD than others, and those with COPD who are poorer are particularly struggling. Poorer people with COPD have more exacerbations,¹⁶ and the poorest people with COPD are being left further behind in terms of the care that they are receiving.

- **Someone from the poorest 10% of households is more than two and a half times more likely to have COPD than someone from the most affluent 10% of households.**

ii NHS QOF data indicates that in England in 2021/22, 36.9% of eligible (grade 3 or above on the MRC breathlessness scale) people with COPD were offered a PR course for the first time. See here: <https://digital.nhs.uk/data-and-information/publications/statistical/quality-and-outcomes-framework-achievement-prevalence-and-exceptions-data/2021-22> and here: www.pcrs-uk.org/mrc-dyspnoea-scale for further information.

iii See Table 1 on p. 22 for further information.

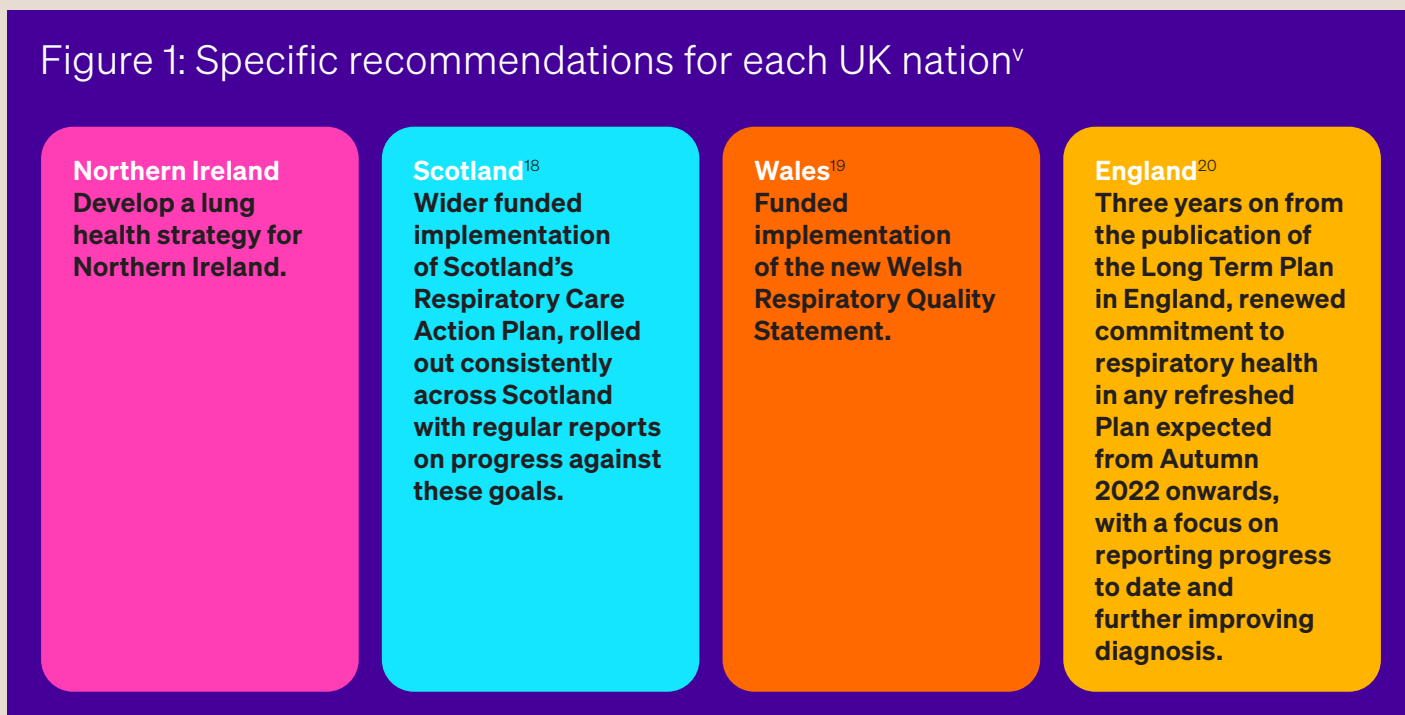
Policy recommendations

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

- **Implement a pre-diagnosis breathlessness pathway,^{iv} to improve the speed and accuracy of diagnosis within primary care.**
- **Prioritise urgently increasing the capacity for timely, quality assured spirometry across the system, particularly in primary care, so that this is available universally.**
- **Run a public awareness campaign on key symptoms, such as breathlessness,** to encourage people to seek diagnosis and treatment.
- **Include lung health in all inequalities strategies.**
- **Ensure timely case finding amongst high-risk groups** (such as smokers, people experiencing homelessness, those who are poorer or in a high-risk occupation) to identify COPD and other lung conditions, so that these can be treated sooner.
- **Ensure services maximise the opportunities provided by Targeted Lung Health Checks,** to make sure that evidence of conditions other than lung cancer is not ignored.
- **Address inequalities** through both case finding and Targeted Lung Health Checks by focusing on areas of deprivation, where COPD prevalence is lower than expected.
- **Prioritise lung health in the implementation of all national health strategies,** such as the refreshed NHS Long Term Plan.
- **Smoking cessation:** the Government must move swiftly to implement the recommendations of the Khan review:¹⁷ making smoking obsolete immediately, including adequate funding (from a levy on the tobacco industry) for local authorities to support smokers wishing to quit to do so.
- **Urgently develop an NHS Workforce Strategy** to address the capacity and capability gaps in primary care, and to adequately resource community and secondary care services which have been overwhelmed by COVID-19.
- **Air pollution:** raise awareness amongst people with COPD about the availability of air pollution alerts, so they're able to protect themselves from harm.
- **Amend clinical teaching guidelines** and work closely with the health services to ensure healthcare professionals provide sufficient advice on air pollution to people living with lung conditions.
- Invest in further **research and innovation** for COPD.
- **National Asthma and COPD Audit Programme (NACAP):** we also recommend engaging with quality improvement programmes and resources through NACAP, where high-quality local data on the care people with COPD are receiving would be useful.

^{iv} Modelled on the Diagnostic Pathway Support Tool, developed in England for adults presenting with chronic persistent breathlessness of more than 8 weeks' duration.

Figure 1: Specific recommendations for each UK nation^y



Specific recommendations for clinical education and practice

The following recommendations are more relevant to clinical practice. However, many of these clinical goals cannot happen without support from decision makers within the four governments across the UK. Policymakers have a role to play to ensure adequate support for clinicians to overcome potential barriers to achieving these goals, as healthcare professionals cannot achieve these recommendations alone.

Spirometry and case finding in primary care and the wider system:

- The most impactful change that healthcare leaders in respiratory healthcare can make is to do what they can to ensure quality assured spirometry testing (a key test for the accurate diagnosis of COPD) is easily and quickly accessible.

Spirometry is a simple test which is essential for an accurate diagnosis of COPD. This involves blowing hard and fast into a machine that measures your lung capacity. This measures the total amount of air you can breathe out, and how quickly you can empty your lungs.

Greater attention to capacity and capability across primary care (both knowledge and skills) and resourcing in the wider NHS would help patients to receive quality assured spirometry, as part of a full and holistic diagnosis process and ongoing monitoring and management.

- **Ensure evidence of COPD found at Targeted Lung Health Checks (TLHCs) is not ignored.** We hope to see the inclusion of spirometry as the optimum protocol and pathway is determined for the implementation of screening across the UK.²¹

Renewed provision of care levels prescribed in the NICE clinical guidelines²² is needed.

- All five fundamentals of COPD care²³ should also be made a core part of undergraduate and postgraduate medical training.
- Ensure all those who could benefit from access to pulmonary rehabilitation (PR) are able to access it.
- Smoking cessation: ensure all the proposals in the Khan review²⁴ are followed, especially funding for comprehensive stop smoking services.

What can people with diagnosed or suspected COPD do next?

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

- Complete our **COPD Patient Passport** to find out if you are getting the care you need and deserve. It produces a report which you can discuss with your doctor or nurse.
- Download and use our **COPD self-management plan**. Our self-management plan is designed to help you manage and understand your condition.
- For advice, call our helpline on **0300 222 5800**. Lines are open 9am–5pm, Monday to Friday. You can also email us via **helpline@asthmaandlung.org.uk**.
- **Join a support group** online or near you.
- **Read our webpages on COPD** to learn more about the condition.
- **Learn how to use your inhaler**.
- **Read information about welfare benefits**.

Introduction

The findings in this report are from Asthma + Lung UK's second survey of people with COPD. We found: delays and barriers to accurate diagnosis, a decline in the quality of care received by people with COPD, and a disproportionate impact of deprivation for poorer people with COPD.

What is COPD?²⁵

Chronic obstructive pulmonary disease (COPD) is the name for a group of lung conditions which make it more difficult to breathe air out of the lungs, due to a permanent narrowing of the airways and destruction of lung tissue. These conditions include long-term (chronic) bronchitis and emphysema.

COPD is a permanent narrowing of the airways caused by long-term damage to the lungs. It is a progressive and incurable condition but can be controlled with treatment and self-management. COPD affects people in different ways. Some people with the condition only have mild lung damage and few symptoms. In severe cases, other people have very damaged lungs and can feel very breathless and limited in what they're able to do.

Key symptoms include: getting short of breath easily, having a cough that lasts a long time, wheezing, or coughing up more phlegm or mucus than usual.²⁶ Some people with COPD live with these symptoms all the time. Others may notice that their symptoms worsen when they have an infection, or breathe in smoke or fumes.

Many people with COPD have to reduce their working hours, retire, or die earlier than others without the condition. COPD can impact a person's life and impose restrictions on their way of life in many ways.

Headline survey findings

Chapter 1: The journey to diagnosis

Diagnosis has gone from bad to worse: experiences of diagnosis were poor before the COVID-19 outbreak, and now the pandemic backlog has exacerbated this.

- **12.4% of respondents (one in eight) waited more than 10 years for a diagnosis.**
- **A quarter of people surveyed are waiting five years or more for a diagnosis:** nearly one in four people with COPD waited more than five years to be diagnosed.

Accurate diagnosis is critical to ensure that people can receive the right treatment for their condition. Where diagnosis is inaccurate or delayed, people may receive inappropriate treatment for their condition, or lack the treatment that they need. People with COPD often have multiple causes for their symptoms, which also require a diagnosis.

Chapter 2: Quality of care

COPD is the name for a group of lung conditions where it's difficult to breathe air out of the lungs. It causes a permanent narrowing of the airways and destruction of lung tissue. Our 2022 survey asked people for the second time about the quality of care they have received for their COPD in the last year. Our survey shows:

- **Quality of care has plummeted for people with COPD:** levels of routine care have dropped lower than last year's levels.
- **UK-wide, the number of those that had received the full package of care (all five fundamentals²⁷ outlined above) has dropped from 24.5% to just 17.6%, a reduction of 6.9 percentage points.**
- This means less than a fifth of people with COPD surveyed received recommended levels of care.
- **Overall levels of five fundamentals (5F) care provision have dropped in every nation**, most prominently in England (from 26% in 2021 to 18.4% in 2022).
- **Only 21.6% had received spirometry in the last 12 months**, despite guidance published in April 2021 (a year before our survey closed) indicating that spirometry is safe.²⁸

People who receive all five core elements of COPD care have better outcomes, fewer flare-ups and a better knowledge of how to manage their condition.²⁹ Those who are not receiving the 'five fundamentals'³⁰ of COPD care are missing out on the best care, which could in turn impact the severity and management of their condition.

Chapter 3: The need to address health inequalities

- Poorer people with COPD have more exacerbations.³¹
- The poorest people with COPD are being left further behind.
- **Someone from the poorest 10% of households is more than two and a half times more likely to have COPD than someone from the most affluent 10% of households.**

Chapter 1: The journey to diagnosis

In last year's survey report,³² we highlighted the difficult journey many people with COPD are forced to take before they get a diagnosis. Failure to identify potential COPD symptoms, limited provision and access to care and variable quality of diagnostics were the key problems for people with suspected COPD. In this year's survey we asked further questions on people with COPD's experiences of diagnosis. This chapter will explore these issues and offer solutions on how to improve diagnosis for people with COPD.

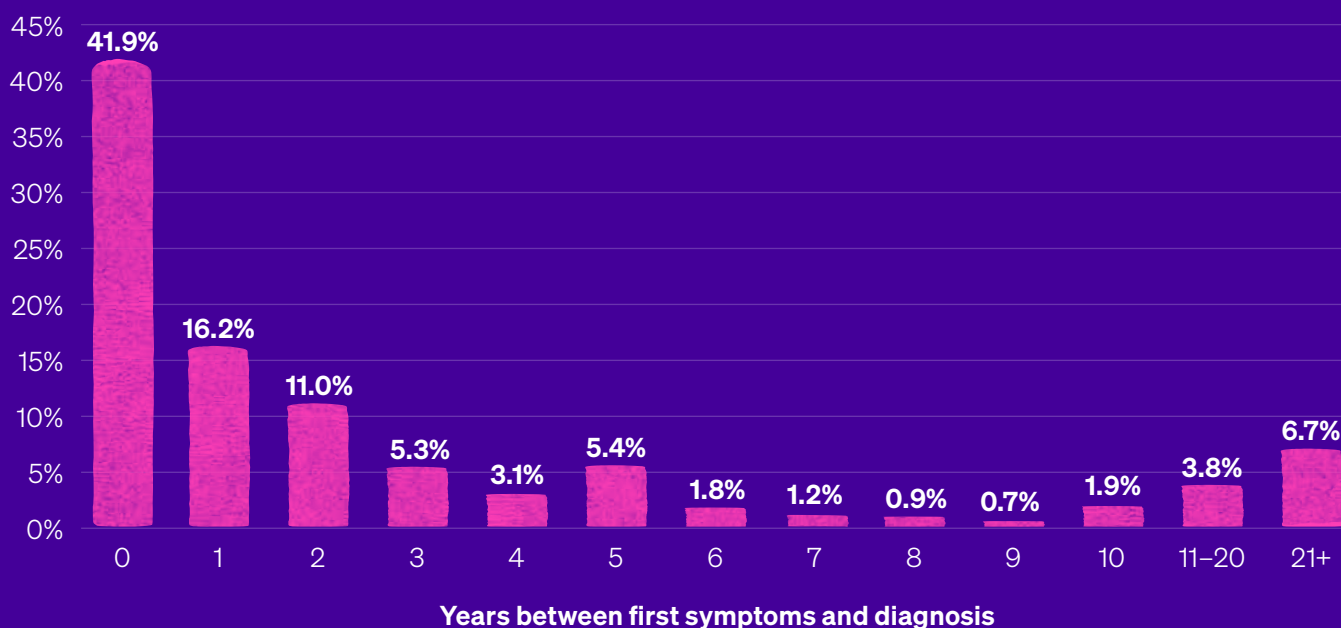
Delays and barriers to diagnosis

NICE indicates:

“Prevalence [of COPD] increases with age and most people are not diagnosed until they are in their 50s. There are significant geographic variations in the prevalence of COPD, and it is closely associated with levels of deprivation. Unlike many other common chronic diseases, the prevalence of COPD has not declined in recent years.”³³

Getting a COPD diagnosis should be straightforward, based on symptoms, risk factors and simple tests of lung function (spirometry). Instead, it is often the culmination of a protracted period of deteriorating symptoms and missed opportunities.³⁴ Ideally, the path from spotting potential COPD symptoms to getting a diagnosis should include clinical tests, a full discussion of the person's clinical history, and the person with COPD should be well-informed about their condition at the end of the process. The time taken along this pathway should ideally be measured in weeks rather than months or years. We asked our respondents for their age when they first noticed COPD symptoms, and the age they received a diagnosis.

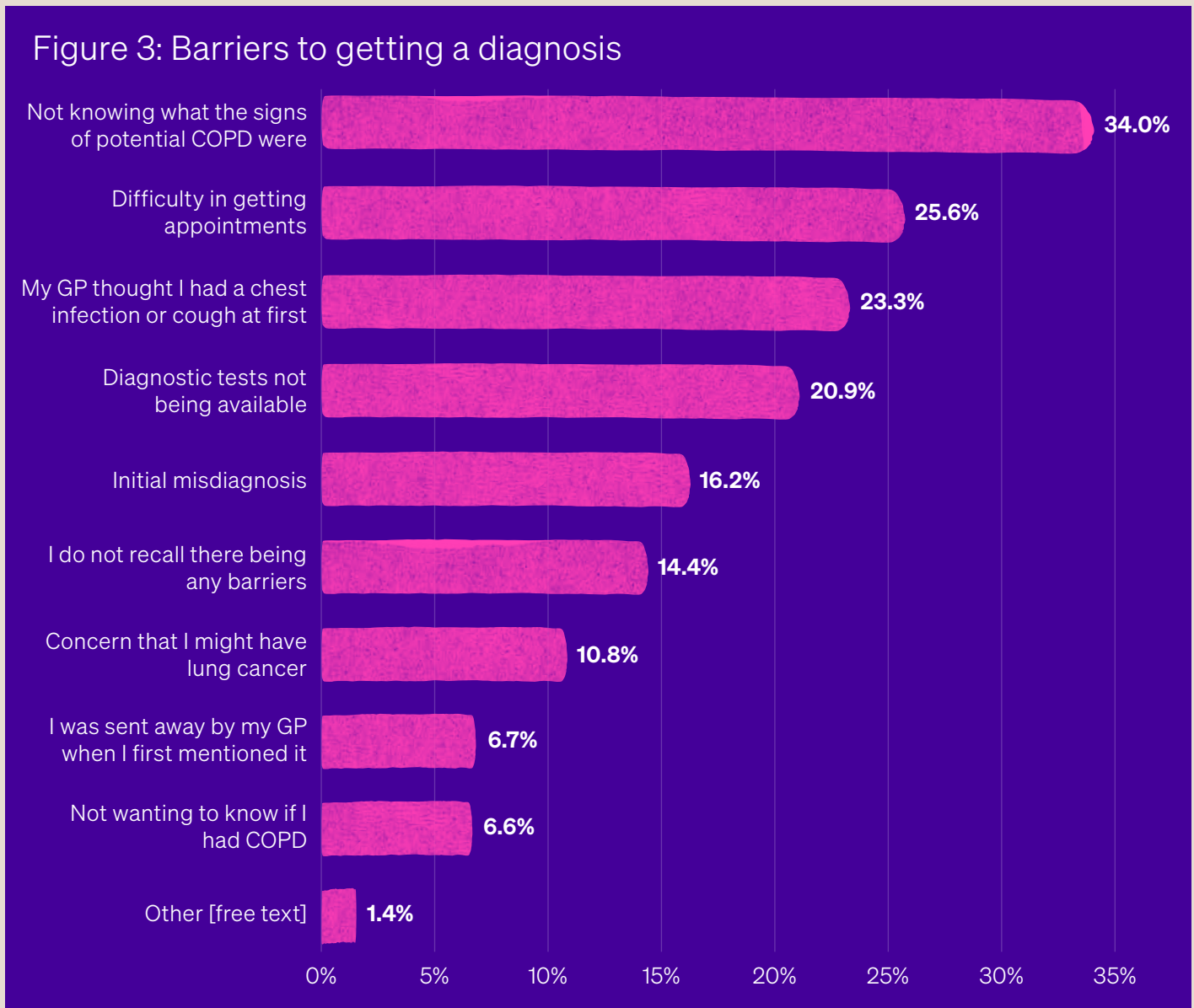
Figure 2: Years waited between first noticing symptoms and receiving a diagnosis



While a majority of respondents (58.1%) had waited a year or less, one in eight (12.4%) people with COPD waited more than ten years for a diagnosis after first noticing symptoms. This is a very long time to be living with symptoms that can reduce activity levels, impact upon work and life opportunities and affect mental health. In addition, anyone living with undiagnosed COPD is at increased risk of flare-ups (acute exacerbations of their symptoms) or chest infections, which may not then be treated as readily. Available evidence from NICE published in 2011, and last updated in 2016, indicates that up to an estimated two million people in the UK could be living with undiagnosed COPD.³⁵ However, these figures may not reflect the current situation. More up-to-date research is needed to accurately understand the numbers of people living with undiagnosed COPD. Nevertheless, this data indicates that getting a diagnosis can take a substantial amount of time.

We asked how long people waited to see a healthcare professional to speak about their symptoms, and 36.1% waited more than a year before seeking help. This is crucial missed time, where new symptoms are going unassessed and unmanaged, and highlights the need to greatly improve public awareness of lung health and when to seek medical advice for key symptoms. Giving people the information they need to take this first step faster will enable people with COPD to get a diagnosis and the right treatment to manage their condition in a more timely manner.

When we asked what the barriers were to getting a COPD diagnosis,^v not knowing what the signs of potential COPD were was the most common answer (34.0%).



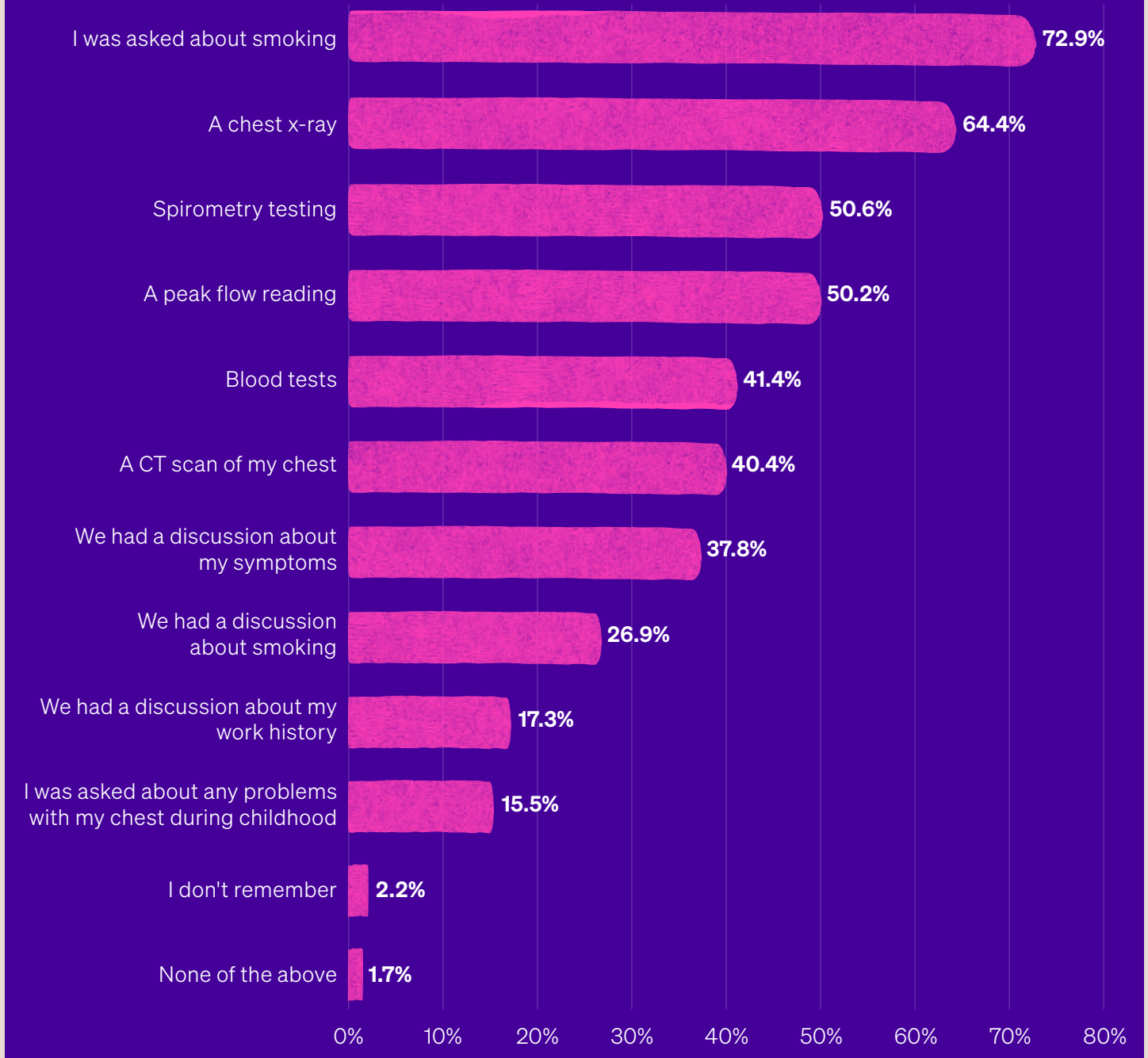
COPD does not have the profile a condition of its impact and seriousness warrants, and it is understandable that some people may not know what the potential signs of COPD are. However, those more at risk could be targeted via proactive case-finding, with support to know what symptoms to look for, and when to best raise them with a healthcare professional. Winter chest infections might indicate underlying COPD but too often the focus is just on treating the infection. Introducing a pre-diagnosis breathlessness pathway may also help find people with COPD earlier. It is not just people with undiagnosed COPD who do not always know the signs. Being misdiagnosed, the healthcare professional thinking it was a chest infection or cough at first and even being sent away by a clinician when the new symptoms were mentioned, were reported by 46.2% of respondents in total. Other barriers cited relate to capacity issues. A quarter (25.6%) found it difficult to get an appointment, and one in five (20.9%) reported diagnostic tests not being available when needed.

^v For this question, we only asked those who were diagnosed in the past two years.

Diagnostic testing

This highlights how even being able to talk about new COPD symptoms is not always a straightforward process. Given the problems already encountered, it is not a surprise that the quality of diagnosis is variable. According to clinical guidelines, spirometry testing is required to confirm diagnosis.^{36,vi} Only 50.6% of respondents diagnosed in the past two years recalled having this crucial test done as part of their diagnosis. This is despite instructions from national health services to restart spirometry, and to pause the Quality and Outcomes Framework (QOF) to focus on higher-risk groups during the restart. COPD was one of the high-risk groups highlighted. Although spirometry is no longer included within the Quality and Outcomes Framework (QOF) for England, Wales and Northern Ireland for annual COPD reviews, it is still included at the point of diagnosis, as it is essential to ensure accuracy at this stage. This is a clear shortfall in diagnostic care that needs to be addressed.

Figure 4: What happened in your COPD diagnosis?



vi As well as this test, a chest x-ray and blood tests should take place. The healthcare professional should also have a discussion with the person with suspected COPD covering symptoms, exposure to risk factors (such as smoking or occupational) and medical and family history.

Other key elements of diagnosis that survey respondents did not receive include a chest x-ray (64.4% received), blood tests (41.4% received) and a discussion about work history (17.3% received) (Figure 4). Having this range of diagnostic tests gives a more complete picture of the complexity of COPD, and gets the person with COPD the most appropriate treatment. Talking about work history and previous lung health history (as well as smoking history) also gives a fuller picture in the diagnosis. Spirometry, along with many other services, was severely disrupted during the pandemic. Up to 46,000 people missed out on a COPD diagnosis in 2021,³⁷ driven by lack of access to services such as spirometry. These results are a legacy of that, and provision of key diagnostic services is still not at the level it needs to be. However, clear guidance indicates that is now safe to restart spirometry.³⁸

Once a diagnosis has been confirmed, most people with COPD (63.4%) surveyed told us that they did not feel fully prepared to manage their condition. Less than one third (30.7%) were given material (such as leaflets or links to support groups) to support managing their condition. This is the bare minimum that should be provided – having a co-designed self-management plan should be aimed for. Being supported in self-management is crucial to managing a long-term condition. Providing support and resources after diagnosis is an important opportunity to embed knowledge and management routines. For most people with COPD, this has not happened.

This section shows some of the problems people with COPD have had with getting a diagnosis for their condition. More interventions are needed to reduce the amount of time people live with untreated symptoms, and more support is needed once they are diagnosed.

Katy's story



Katy Brown, 64, a retired nursery nurse from Bristol, was diagnosed with COPD in February 2021.

She says: “Everything about my COPD experience has been an absolute battle and it doesn’t surprise me that people are having to wait so long to be diagnosed or to get the help they need.

“My breathing first became an issue in 2019 and I went backwards and forwards to the doctor with constant chest infections, but I was repeatedly fobbed off. Finally in February 2021, I managed to speak to a respiratory nurse over the phone who confirmed my diagnosis but because we were in the middle of the pandemic, I wasn’t given a spirometry test to check on the state of my lungs.

“And that was it – no follow-up, and no guidance. I’ve had to find out everything for myself which has been exhausting. I honestly believe that if I wasn’t such a forceful character, I’d still be waiting for a diagnosis and answers, as I was told nothing.

“Shortly after I was diagnosed, I joined one of Asthma + Lung UK’s Breathe Easy groups which has been brilliant. It was there that I found out about pulmonary rehab, and I nagged and nagged my GP to get a referral, and I’m so glad I did, as for me, it has been an absolute game-changer.

“I know I am one of the lucky ones, but there are so many people with COPD who are simply being left behind, and that isn’t right. Nobody should have to fight to get a diagnosis or basic levels of care.”

Policy recommendations

- **Pre-diagnosis breathlessness pathways in every UK nation:**

To address barriers to diagnosis, we are calling for health services in all four UK nations to roll out pre-diagnosis breathlessness pathways.

A pre-diagnosis breathlessness pathway is currently being piloted in England.^{vii} We want to see this fully implemented within community diagnostic centres (CDCs), as well as across general practice and any other settings where COPD may be suspected (such as Accident and Emergency, walk-in centres, and non-respiratory specialities in secondary care).

In the devolved nations, we would like to see Scotland, Wales and Northern Ireland follow and implement their own breathlessness pathways, so no one in the UK experiencing key symptoms, such as being short of breath, is left behind.

- **Service leaders and NHS management across the UK should prioritise urgently increasing the capacity for timely, quality assured spirometry across the system, particularly in primary care, so that this is available universally:**

Spirometry testing, which is essential for the accurate diagnosis of COPD, was paused during the pandemic, due to what were at the time understandable concerns about how to administer these tests in a COVID-safe way. Despite clear guidance now advising it is safe to resume spirometry, as it is not an aerosol-generating procedure,³⁹ many GP surgeries have not yet restarted services. This must be urgently remedied to give people with suspected COPD the accurate diagnosis they need, as part of a detailed clinical assessment.

The most impactful change that healthcare leaders working in respiratory healthcare can make is to act to facilitate the restart of quality assured spirometry, a key test for the accurate diagnosis of COPD.

However, we recognise that this cannot happen without central support from the four governments across the UK. Policymakers, NHS management and commissioners all have a role to play to ensure adequate support for clinicians to overcome potential barriers, as healthcare professionals cannot do this alone.

For example, funding is needed for refresher training to reskill the workforce.

The impact of the pandemic has created a double burden for people with COPD, due to pressures on the respiratory workforce affecting the delivery of respiratory care, beyond treatment of COVID-19: not only reducing diagnosis rates but also absorbing finite respiratory resources, such as testing and workforce expertise, which are now managing acute and long COVID, rather than addressing the backlog for people with COPD. This is because COVID-19 is a respiratory condition with similar symptoms, such as breathlessness, and related complications.

A recent report by the British Thoracic Society⁴⁰ outlines the need for increased capacity across the whole respiratory multidisciplinary team, and for better training and development for the lung health workforce. The Taskforce for Lung Health^{viii} is also working together to address workforce issues for respiratory care.

- **Case finding in primary care:**

National health services should amend guidance for GPs across the UK to ensure:

a) proactive management of symptoms such as breathlessness, cough and sputum

and

b) timely case finding amongst high-risk groups (such as smokers, people experiencing homelessness, those who are poorer or in a high-risk occupation) to identify COPD and other lung conditions.

vii As mentioned above, this has been published on the FutureNHS platform, which is accessible to anyone working in health and social care via: www.england.nhs.uk/futurenhs-platform.

viii See www.blf.org.uk/taskforce for further information.

The potential benefits of this are earlier diagnosis and treatment for those most at risk.

To supplement this, it is important that services maximise the opportunities provided by Targeted Lung Health Checks (lung cancer screening via low-dose computed tomography (CT) scan for higher risk groups). It is important that evidence of conditions other than lung cancer is not ignored.

Despite the additional pressures posed by the pandemic, early and accurate diagnosis of COPD could be improved through the development of appropriate pathways for identification and follow-up of high-risk patients. This could help to identify the two million people suspected to be living with undiagnosed COPD UK-wide, who will continue to be disabled by their symptoms until diagnosis, and whose lung function and general health is likely to decline, making it harder to treat.⁴¹

Although clear evidence that early intervention can improve outcomes for patients is needed to justify the additional demand on the health and care system created by developing the pathways to follow these patients up, and ensuring adequate workforce capacity to deliver this, we hear from people with COPD the benefit that earlier access to treatment would make to their quality of life (for example, see Katy's story above). In addition, there is established evidence that one COPD exacerbation can worsen future outcomes.⁴² Therefore it is worthwhile to aim to prevent this through earlier diagnosis and treatment.

Due to the inverse care law, which states that "The availability of good medical care tends to vary inversely with the need for it in the population served",⁴³ areas where poorer people live have fewer GPs, despite their greater healthcare need, which is unfair. Case finding has a crucial role to play in helping to address this inequality, as it will be even more needed in these areas.

- **Better information on the signs of COPD for people at risk, to raise awareness of key symptoms, such as shortness of breath, cough and sputum.**

We are calling for public awareness campaigns on symptoms such as breathlessness to be run in each UK nation, building on the success of the British Lung Foundation's "Listen to your Lungs" campaign.⁴⁴ This is because increased public awareness of when to seek medical advice for key symptoms, such as a long-term cough or breathlessness, is key to improving rates of early and accurate diagnosis. Specific targeting of lesser-heard-from groups and deprived areas is essential to help prevent further delays in these populations, which would further widen health inequalities.

- **Greater investment in research and innovation for COPD:**

Less than 1% of UK research and development funding is spent on COPD, and as a result, the condition is chronically under-researched:

"Even though COPD is the third leading cause of death worldwide, there are currently only 780 ongoing therapeutic clinical trials related to the disease, compared with more than 41000 trials of cancer treatments. This lack of research partly explains the fact that only one new drug class has been approved for COPD in the past three decades."^{45,46}

Greater investment in COPD research could help to resolve issues of poor outcomes for people with the condition highlighted in this report. This is because the lack of research means that approaches used are dated and flawed. Relying on tests to diagnose COPD at a stage where lung damage is well established needs to be addressed. Investing in research could provide new diagnostic tools and interventions that could be used at an earlier stage.

Due to the difficulties in providing spirometry, we need to develop simple, inexpensive and non-invasive alternative tests, ideally to identify COPD at an early stage. Investment and testing infrastructure is needed from those funding research and innovation in this area to achieve this.

Asthma + Lung UK wants to see a tripling of investment in respiratory research and innovation to urgently remedy this, focusing on developing new treatments, diagnosis, self-management and digital solutions for pulmonary rehabilitation (PR).⁴⁷

To do this, more clinical trials are needed to test new developments on real people. This cannot happen without people with COPD being able to access these trials and volunteer to participate where they wish to do so.

Chapter 2: Quality of care

The five fundamentals of COPD care

The National Institute of Health and Care Excellence (NICE) guidelines for diagnosis and management of COPD in adults^{48,49,50} set out the five fundamentals (5Fs) of COPD care, which are:

- Offer treatment and support to **stop smoking**
- Offer **pneumococcal (pneumonia)** and **influenza vaccinations**
- Offer **pulmonary rehabilitation** if indicated (for those 3 or above on the MRC breathlessness scale)⁵¹
- Co-develop a personalised **self-management plan**
- Optimise treatment for **multiple conditions**.⁵²

It is important to note that treatments and plans should be revisited at every review,⁵³ and that timely and accurate diagnosis is also a prerequisite for the achievement of the 5Fs outlined above.

We asked all respondents whether they had received the five elements of COPD care that they were eligible for. In this survey, only 17.6% of people with COPD received all the elements of care that they should have received. This is down from 24.5% in 2021. Each element is not a large intervention on its own, but the whole package needs to be delivered for the best possible care, and for people with COPD to manage their condition, thereby also reducing the impact on the NHS.

Standards of COPD care have declined across the UK

Levels of routine COPD care have fallen even further in every nation in the UK from last year. The drop is particularly marked in England, with rates of 5F provision dropping by 7.6 percentage points. This indicates that the low care levels we saw last year were not simply a consequence of the pandemic's impact on access to care, and that there are more long term issues to address, such as how the public and healthcare professionals perceive chest symptoms and conditions, and how the NHS approaches COPD.

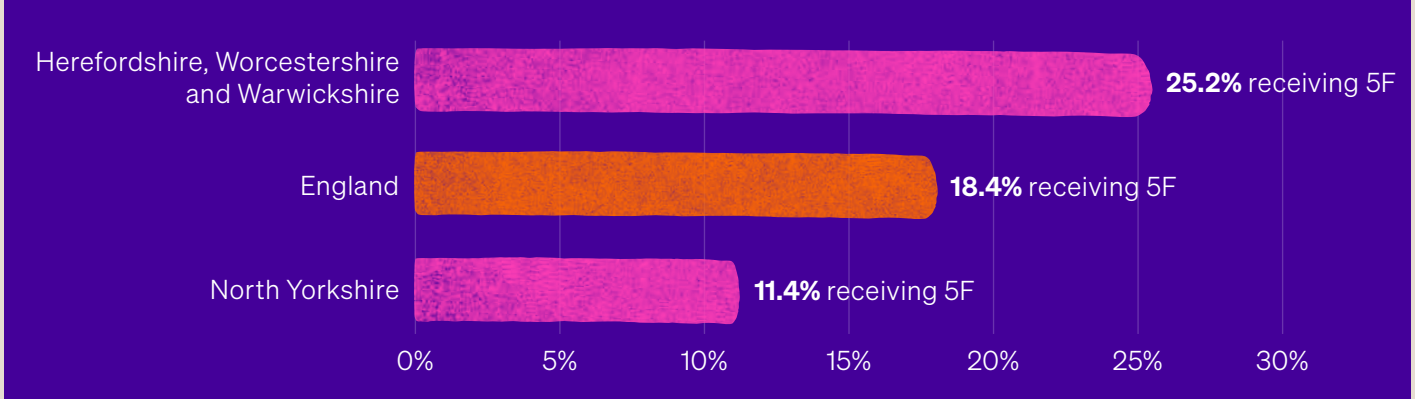
Figure 5: Provision of five fundamentals of COPD care



There has been a decline in the provision of the five fundamentals of COPD in every UK nation this year. Notably, UK-wide the provision of the whole package of care is down 6.9 percentage points this year, compared to 2021's figures. These are unacceptably low levels of care that put people with COPD at risk of exacerbations and hospitalisations.

As well as across UK nations, there is also significant variation in five fundamentals provision in England. Levels range from 25.2% receiving this care in Herefordshire, Worcestershire and Warwickshire, to only 11.4% receiving the care in North Yorkshire. This data shows that care received for COPD has significant variation across the country, and this is one way health inequalities manifest in COPD care.

Figure 6: Highest and lowest levels of five fundamentals provision in England



There has been a decline in all five fundamentals of COPD care, except for the marginal improvement in numbers of those that have an action plan and who have experienced optimised treatment for other long-term conditions (Table 1).^{ix} It is slightly encouraging that these individual elements have not seen dramatic drops in levels of provision, which perhaps indicates that parts of COPD care are functioning to a reasonable level. Despite this, there has been a decline in the delivery of the overall package of good-quality care for people with COPD.

Table 1: Provision of elements of COPD care, 2021–2022

Element of care	% Eligible receiving this element of care	
	2021	2022
Offer treatment and support to stop smoking	55.4%	54.3%
Offer pneumococcal (pneumonia) and influenza vaccinations	90.1% (flu); 68.7% (pneumococcal/pneumonia).	89.4% (flu); 66.4% (pneumococcal/pneumonia).
Offer pulmonary rehabilitation if indicated	50.3%	46.1%
Co-develop a personalised self-management plan	31.7% (have an action plan); 60.4% (co-developed it).	32.1% (have an action plan); 58% (co-developed it).
Optimise treatment for comorbidities	30.3%	31.8%

We will explore the issues around each of these crucial elements of care.

Smoking cessation

Smoking cessation is the most important intervention to stop the progression of COPD.⁵⁴ While not everyone will use the support available to stop smoking, people with COPD who are still smoking need to know this support is available. Stopping smoking can prevent the progression of COPD and improve lung function. Our recommendations for smoking cessation are outlined in more detail in Chapter Three below, and in our **‘Clearing the Smoke’** report, also published this year.⁵⁵

Vaccination

People with COPD need to have vaccinations, such as the pneumococcal vaccine for pneumonia and the flu jab, as diseases like flu can cause serious illness.⁵⁶ Getting these jabs reduces the likelihood of going into hospital, and also reduces the risk of mortality (death).⁵⁷ The winters of 2020–2021 and 2021–2022 did not have severe flu seasons, but this is unlikely to be repeated in winter 2022, as COVID-19 becomes endemic. It is also important that people with COPD are prioritised for COVID-19 vaccination, as they are more vulnerable to respiratory infections.^{58,x}

ix A breakdown for these elements by UK nation is available in Appendix C.

x As recommended by the Global Initiative for Chronic Obstructive Lung Disease (GOLD) guidance, accessed here: <https://goldcopd.org/2022-gold-reports-2>.

Pulmonary rehabilitation

The provision of pulmonary rehabilitation services was particularly affected during the COVID-19 pandemic, as they were previously offered face-to-face. Pulmonary rehabilitation (PR) is a course of physical activity classes that help people with lung conditions, including COPD, stay active. They are usually held in small groups,⁵⁹ and were done face-to-face before the pandemic. NHS Quality and Outcomes Framework (QOF) data indicates that in England in 21/22, 36.9% of eligible^{xi} people with COPD were offered a course,⁶⁰ highlighting the shortfall in provision of this intervention. In 2021, we recommended that it was an urgent priority UK-wide to restart any PR services that were yet to resume:

- 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).⁶¹
- Services should then look to expand access of PR to those with a breathlessness score of MRC grade 2 and above.⁶²

This remains relevant today, as provision of PR services is below the levels we saw in 2021. Those who could benefit from access to PR need to be able to access it.

To help address this, many pulmonary rehabilitation services went online during the pandemic, which some people may prefer, at least for some aspects of the course. Providing that these online classes are quality assured in the same way as face-to-face sessions, it is also important to enable accommodating patient choice for virtual or physical location of PR classes. Delivering PR in new and innovative ways, such as online, digitally delivered programmes that can be completed at home, can help extend capacity of service provision, thereby allowing more people who could benefit to access this service.

To spread this further, new models of delivery could be tested through Academic Health Science Networks, for adoption into more widespread health service delivery.

Self-management

Self-management is crucial to managing lung conditions and keeping their symptoms under control. Self-management means knowing when to seek help with symptoms, and what kind of help to seek. Having education and plans to do this are essential for staying well, and out of hospital. People with COPD need tools and support to do this, and we have seen little progress in these being provided. There is a need for digital self-management solutions that can help to slow the rate of lung function decline, improve symptoms or quality of life. There is emerging data on the efficacy of digital COPD self-management applications and platforms that could complement NHS services in this area as these develop. Funding is needed to test and implement new technologies to address this further.

Furthermore, including people with COPD in the creation of a self-management plan has gone backwards. People with COPD are not as prepared as they need to be to manage their condition. This has a particular impact on poorer people, who are also less able to take part in activities to reduce social isolation and maintain their fitness.

Co-morbidities (other health conditions)

We asked survey respondents whether they had discussed long-term conditions in relation to their COPD with a doctor or nurse, and less than a third had done so. Given the age profile of people with COPD, co-morbidities (such as obesity, mental health issues, cancer, osteoporosis, diabetes, cardiovascular diseases, breathing pattern disorder and gastro-oesophageal reflux) are common and need to be discussed between a person with COPD and their healthcare professionals. Optimising treatment for other conditions is needed: for example, ensuring consideration of COPD is built into cardiovascular disease pathways.

xi This indicator measures people grade 3 or above on the MRC breathlessness scale, who were offered a course of PR for the first time.

Babs' story



Babs Thwaites, 71, a former lecturer from Rainham, Essex, has had COPD since her forties. She says her care has declined rapidly since the start of the pandemic, which has had a negative impact on her mental health.

“When I was diagnosed with COPD, I had never heard of the condition before, and I had no idea that the illness was progressive. It was only when my first husband Colin died from the illness that I realised how serious it was.

“I am a former smoker, and I was diagnosed with COPD after a nasty bout of pneumonia. Although my GP is wonderful, over the years, I haven’t had much medical support and I have never been offered spirometry or pulmonary rehab.

“All sorts of things can cause an exacerbation, the cold and wind, hot weather, stress and poor air quality. During the first lockdown in 2020, I was able to walk my dog Fudge for miles because the air was so clear, and the lack of pollution had an incredibly positive impact on my lung health. It was wonderful, and I wanted it to last forever – but now, I’m often too scared to leave the house as I know I’ll soon be struggling to breathe.

“I lost my second husband, Ted, to Covid and my breathing has been more of an issue ever since, and I am sure stress has had a huge part to play in that, as I have struggled with depression all my adult life. I don’t have children and I have only had one face-to-face appointment for my COPD in the last three years. Medical support practically evaporated during the pandemic, and I feel very much alone.

“I recently had to reorder my rescue medication, which increased my anxiety. I was really worried about being without medication to cope with my symptoms.

“Luckily, I know a lot about COPD, but a condition like this needs to be monitored with in-person appointments, and I feel the care I receive now is the worst it has ever been.”

Summary

Babs' story shows that the five fundamentals have an important impact. Our 2021 survey highlighted clear evidence showing that those who received the five fundamentals had better outcomes: fewer flare-ups and a better knowledge of how to manage their condition.⁶³

In this year's survey data, those who received the five fundamentals of COPD care had, on average, fewer COPD exacerbations (5.1) than those who did not receive this level of care (8.5). This shows just how important it is that the full package of care is provided. Those who received the five fundamentals of COPD care were also better informed about COPD. 89.3% of those who received the five fundamentals of COPD care knew what to do in the event of an exacerbation, compared to 66.7% of those who did not receive the care they needed. 91.7% of people with COPD who received all elements of care knew what all their medicines were for and how to use them, compared to 77% of those who did not receive this care.

The impact of health disparities on the experiences of people with COPD and the provision of the five fundamentals of COPD care is explored further in Chapter Three below.

Where the care of people with COPD has been poor or declined because they are not receiving the five fundamentals of COPD care, this has a critical impact on outcomes for each individual. Without the five fundamentals, they are more likely to experience increased numbers of exacerbations and associated hospital stays, and consequently be less able to control their condition through effective self-management. This can have a significant impact on their quality, and length, of life.

Evidence shows that frequency and severity of COPD exacerbations is associated with risk of future exacerbations and death.⁶⁴ Therefore there is a strong case for good basic care, promoting self-management and early intervention to maximise the health and wellbeing of people with COPD.

Policy recommendations

- **Renewed provision of care levels prescribed in the NICE clinical guidelines is needed.**⁶⁵
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.
- **National Asthma and COPD Audit Programme (NACAP):** we also recommend engaging with quality improvement programmes and resources through NACAP, where high-quality local data on the care people with COPD are receiving would be useful.
- **We urgently need an NHS Workforce Strategy** to address the capacity and capability gaps in primary care, and to adequately resource community and secondary care services which have been overwhelmed by COVID-19.
- **In devolved nations: we are calling for the prioritisation of lung health in the implementation of national health strategies.**
Following the prioritisation of lung health in England's Long Term Plan for the NHS,⁶⁶ we are calling for the funded implementation of Scotland's Respiratory Care – Action Plan: 2021 to 2026⁶⁷ and the Welsh Respiratory Quality Statement.⁶⁸ Northern Ireland is the only part of the UK without a respiratory plan, and we continue to call for a new Lung Health strategy there. Civil servants must work with clinicians and patients to improve respiratory care in all UK nations.

Chapter 3: The need to address health disparities

The Marmot Review highlighted that there is a life expectancy gap between the richest and poorest in England.⁶⁹ People in poorer areas not only die sooner, but also spend more of their shorter lives with a disability.⁷⁰

Poorer people with COPD are experiencing worse quality care since the COVID-19 pandemic. Nearly two thirds of materially deprived people^{xii,71} (65.0%) told us their care had worsened because of the pandemic, compared to 50.3% of respondents who aren't materially deprived. COPD is more likely to affect poorer people.⁷² Poorer people are also suffering from more frequent exacerbations of their COPD.

Chapter Two above explored delivery levels of the NICE five fundamentals of COPD care,⁷³ and showed how care levels can vary depending on where you live in the UK. This chapter explores in more detail how the decline in care quality has particularly impacted self-management for people with COPD who are poorer.

Poorer people with COPD are having more exacerbations or flare-ups of their COPD, where their symptoms become particularly severe.⁷⁴ This leads to increased rates of hospital admissions, and increased corticosteroid and antibiotic prescribing. This means their condition is not as well controlled, and their lives suffer more negative effects of living with the condition than those who are wealthier.^{xiii}

This gap in outcomes for poorer people needs to be addressed.

Causes of COPD: the impact of health inequalities

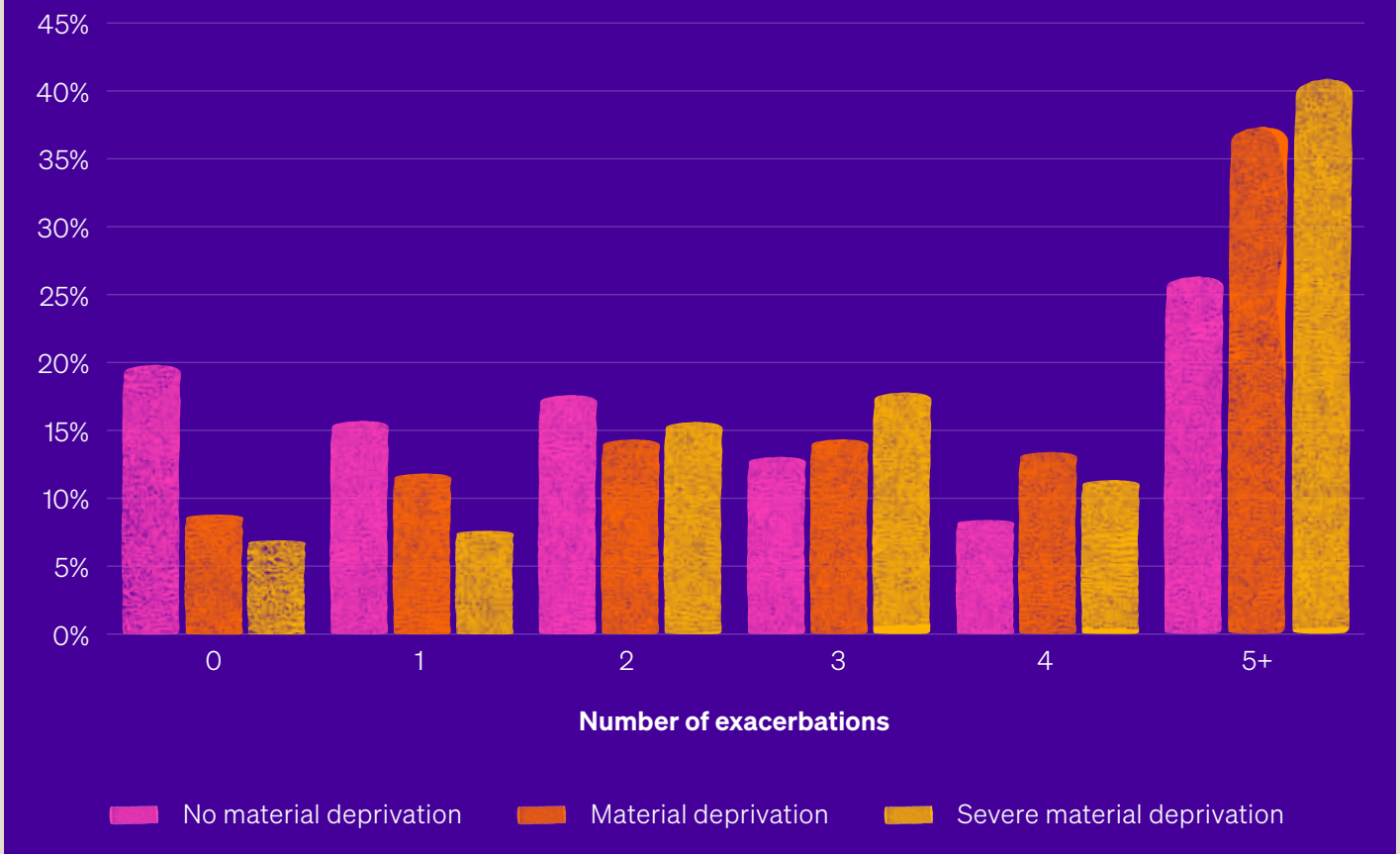
Recent work from Asthma + Lung UK^{75,76} and other key evidence on factors linked to COPD severity⁷⁷ demonstrate that the most common causes of COPD are a history of smoking and adverse early life environment. This is why it's key that prevention begins in childhood and early adulthood.

In addition to being disproportionately affected by the COVID-19 pandemic, someone from the most deprived section of society is two-and-a-half times more likely to have COPD as someone from the least deprived section of society.^{78,79} As well as being more at risk of developing COPD, our survey found that materially deprived people suffered more COPD exacerbations, and were less equipped to self-manage their condition, than those who are wealthier.

xii To assess levels of deprivation, we asked questions based on Eurostat's material deprivation questions. These questions ask whether respondents can afford certain items, ranging from one week's holiday away from home, to being able to pay for regular meals with meat/protein in. Those answering four or more items they could not afford were classed as severely materially deprived, three answers as materially deprived, and two or fewer as not deprived.

xiii The impact of ethnicity on COPD has not been assessed in this report, because the survey did not gain enough respondents who are not white to be representative.

Figure 7: Number of COPD exacerbations in the past 12 months, by level of material deprivation

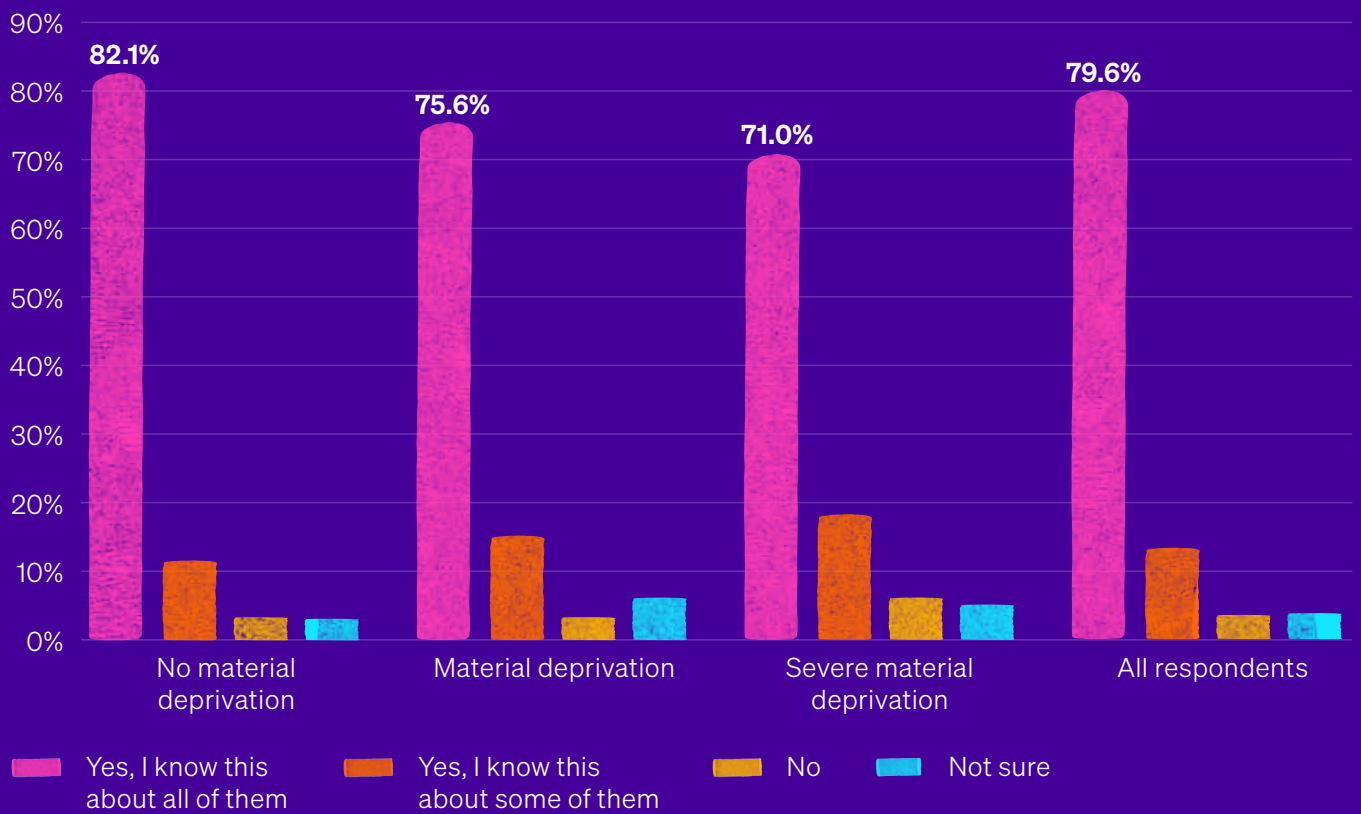


19.7% of people who were not materially deprived had no COPD exacerbations in the past year, compared to only 6.9% of the most deprived group. At the other end of the scale, 40.8% of the most deprived group had 5 or more exacerbations in the past year, compared to 26% of the group who aren't deprived.

With the right interventions to target those at risk, this disparity could be addressed. However, care levels do not come close to helping this situation. For all people with material deprivation, only 14.5% of people received all five fundamentals of care, compared to 18.7% of the group with no material deprivation. Levels of care are low for all people with COPD, but parity in these levels of provision is something to aim for.

Digging deeper into data on care levels, further disparities are found. Being able to self-manage your condition is essential in avoiding COPD exacerbations, and one of the five fundamentals is about having a personalised self-management plan that is co-produced between a person and their healthcare professional. In this measure, we once again find disparities between the materially deprived (13.1% co-producing a self-management plan, compared to the 20.7% of those who aren't). With these varying levels of self-management tool provision, it is sadly not a surprise that those who are the most materially deprived have a lower level of knowledge of what their medicines are for, and how to use them (Figure 8). Being unprepared to prevent and manage exacerbations are the very real consequences of this essential care not being provided.

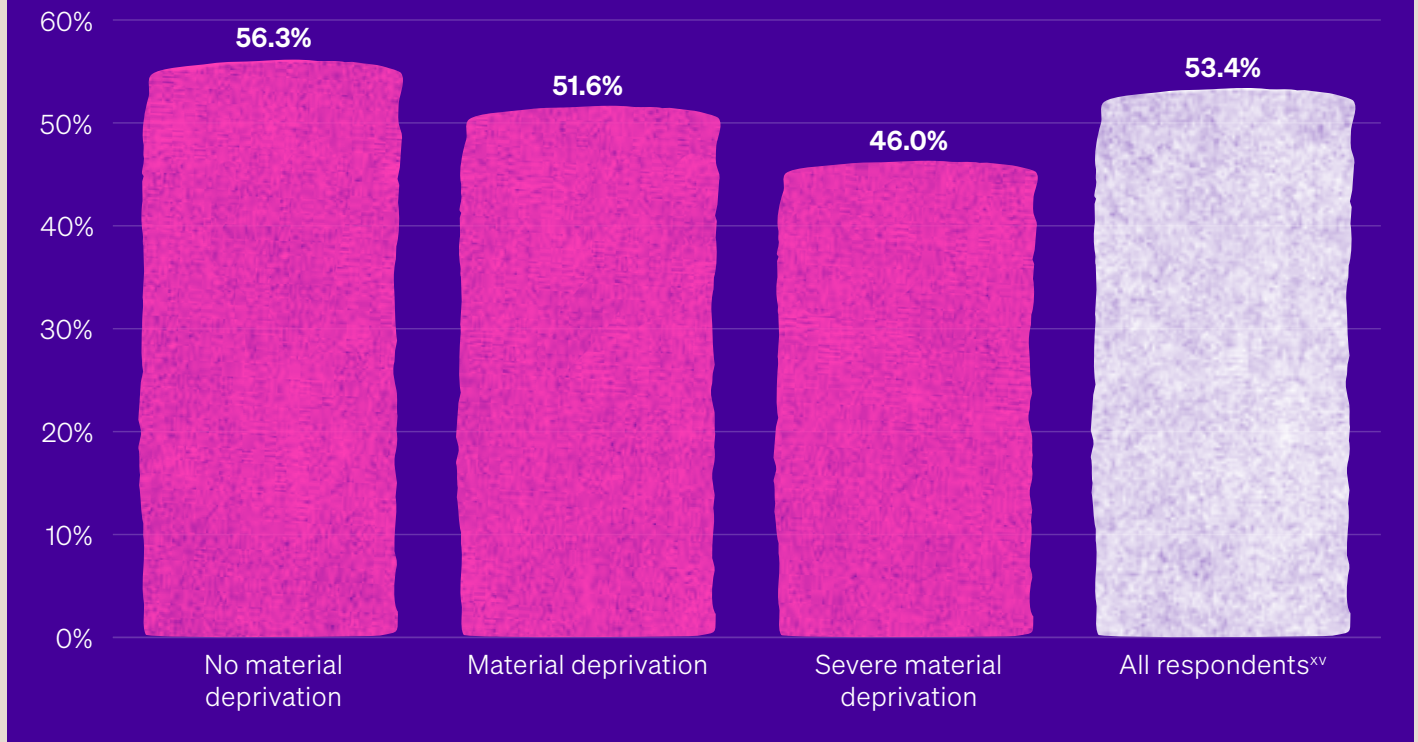
Figure 8: Proportion knowing what their medicines are for and how to use them, by material deprivation level



The importance of smoking cessation

A history of smoking is the most common factor in receiving a COPD diagnosis. Carrying on smoking after diagnosis causes a further decline in lung function and health. Smoking cessation is key because smoking drives acute COPD exacerbations.⁸⁰ Stopping smoking is the highest-value intervention that can be made to reduce the impact of COPD symptoms, improve quality of life and reduce exacerbations. Given the importance of this intervention, equitable access to smoking cessation services should be of the highest importance.

Figure 9: Percentage eligible who have been offered smoking cessation treatment and support, by material deprivation level



Our data shows differing levels of access to smoking cessation services. Only 46.0% of those with severe material deprivation were offered access, compared to 56.3% of the least deprived group. This is an unacceptable gap in provision, and more deprived people with COPD are being failed in this measure. A higher proportion of people with no material deprivation (40.0%) quit smoking with one attempt than those with severe material deprivation (35.5%).

There is real concern that smokefree targets will not be hit. In England it is now clear that targets towards the Government's 'Delivering a Smokefree 2030' commitment could be missed by 7 years, as made clear in the Khan Independent Review of Tobacco legislation,⁸¹ and discussed further in our recent report.⁸²

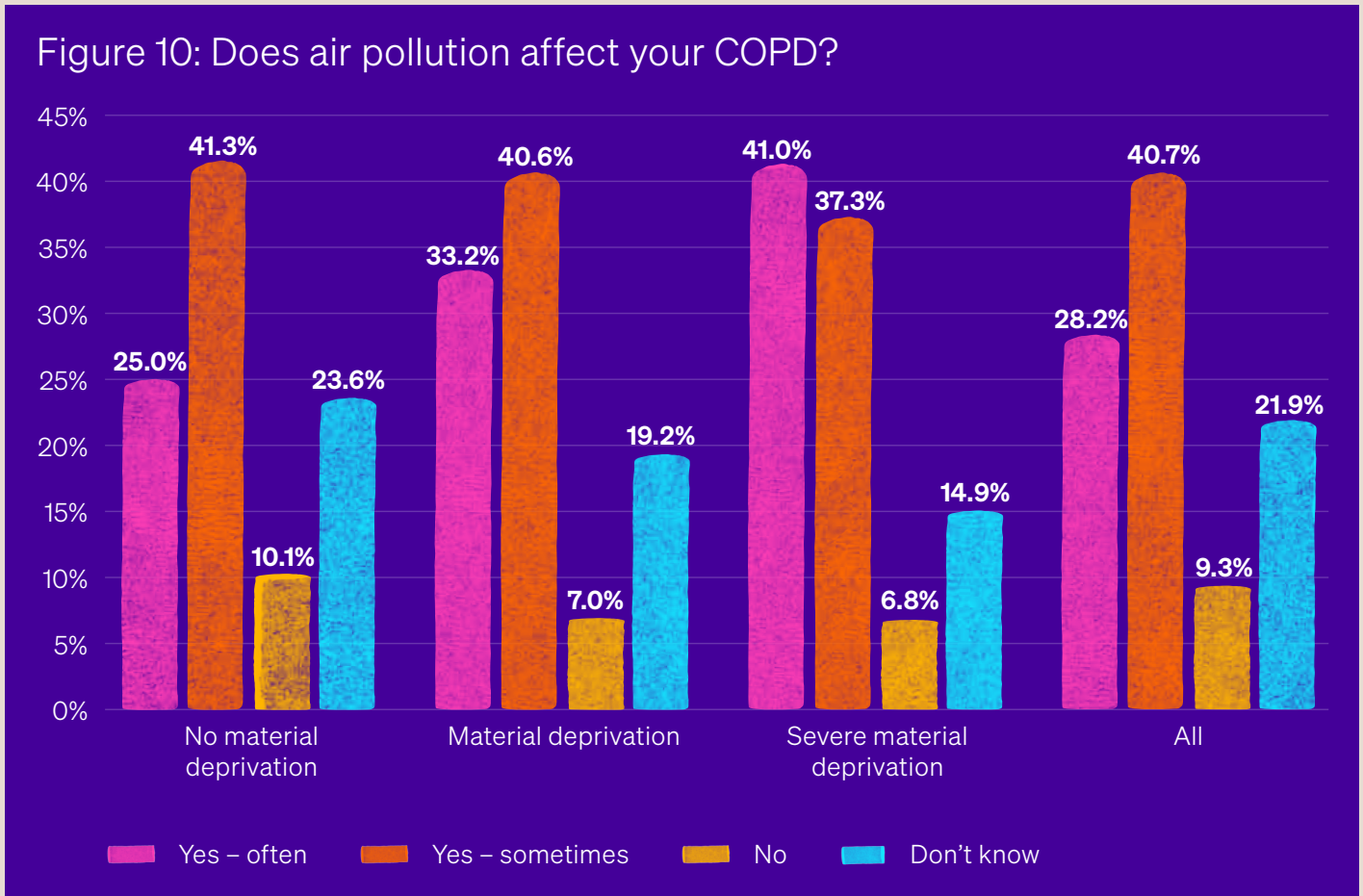
The government must implement a smokefree 2030 fund to increase funding for smoking cessation and related services. A 'Polluter Pays' levy on tobacco industry profits in the UK would be simple to implement and easily raise sufficient funds for proper smoking services across the UK, mass media campaigns, and other tobacco control measures.⁸³

In Scotland it has been estimated that the 2034 target could be missed by as much as 16 years, based on current smoking trends.⁸⁴ Both governments are still committed to their targets, the Welsh Government has since committed to a 2030 smokefree target, whilst Northern Ireland is considering a mid-2030s target. There is a need for renewed action to ensure these can be delivered.^{85,86,87,88}

xiv The figure for all respondents differs slightly from that in Chapter 2. This is because it is only counting those who provided answers relating to their deprivation status (which was not a compulsory question).

Impact of air pollution

Exposure to air pollution increases the risk of COPD and of worsening symptoms or flare-ups.⁸⁹ Air pollution often affects poorer people more than wealthier people. This is despite them contributing least to its development, due to lower rates of car ownership.⁹⁰ Poorer people may also experience multiple overlapping risk factors, such as living by busy main roads, or genetic factors, such as being Black or Asian.^{91,92,93} This is borne out in our survey results. When we asked if air pollution affects COPD, 41.0% of those experiencing material deprivation said that that it often did, compared to 25.0% of the more affluent group.



When we asked those who told us that air pollution affected their COPD, 90.5% of people with COPD said it made them more breathless, 59.2% said they weren't able to walk as far, and 59.2% said it made them use their medication more often. Air pollution has a clear impact on symptoms, quality of life and medicine dependency for the majority of people with COPD, but those in the poorest communities are being acutely affected. The impact of air pollution must be considered within the health inequalities agenda to address this.^{94,95}

Felicity's story



Felicity Payne, 66, a language teacher from Eastbourne, believes early material deprivation made her more vulnerable to developing COPD.

She says: “When I first developed breathlessness seven years ago, my GP told me that everyone gets a cough from time to time, but I knew there was something wrong and I fought to get a diagnosis. I now question my practitioners very carefully as the care I have received has not been very good. For instance, I recently had my annual check-up, and my healthcare professionals missed this opportunity to check my inhaler technique.

“Because COPD tends to affect older, less affluent people, not everyone can advocate for themselves as I do. There is also so much shame attached to the illness because of its association with smoking.

“The best doctor I have ever seen paid much more attention to my childhood which was marked by poverty. As one of four children to a single mother, who also went on to develop COPD, I grew up in a cold, damp council house with not enough to eat and an open coal fire. All the adults in my life smoked, and our house was on a busy road with lots of pollution. I am convinced that such an impoverished start contributed to my lung condition, and it makes me sad that so many children are living in poverty as I did. Health inequalities seem to be widening, and their impact will be felt for generations to come.”

Policy recommendations

- **UK governments should ensure that lung health is included as a key priority in all plans to address inequalities, given its huge role in driving inequity.**

Lung conditions need to be highlighted in the health inequalities debate:

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 lesser-heard-from or disadvantaged groups of people. These plans should focus on preventative measures, such as vaccination, and tackling underlying risk factors, such as air pollution and smoking.

- **We want to see public awareness campaigns run across UK nations,** to improve understanding of lung conditions and when to seek medical advice for symptoms such as a long-term cough or breathlessness. These campaigns should be upweighted within more deprived populations, where disproportionate numbers of those with COPD are likely to be found.
- **Ensure evidence of COPD found at Targeted Lung Health Checks (TLHCs), either CT scan abnormalities or symptoms such as cough, wheeze, sputum, recurrent chest infections or breathlessness are not ignored.**

This requires appropriate safety netting, with clear plans for timely follow-up to further assess all findings that are abnormal, or suggestive of an alternative condition. This will facilitate early and accurate diagnosis and improved outcomes for patients as a result.

Lung screening, such as that provided by TLHCs, also provides opportunities for further research in this area to improve early diagnosis.

The National Screening Committee recently recommended lung cancer screening for people aged 55–74 who are current or former smokers to be integrated with smoking cessation services, pending further modelling work to refine its recommendations, and address implementation challenges.⁹⁶ All individuals with respiratory symptoms in this context require investigation, including spirometry to establish the cause. We hope to see the inclusion of spirometry as the optimum protocols and pathway are determined for the implementation of screening across the UK.

Another opportunity to broaden access to quality assured spirometry and improve diagnosis rates for people with suspected COPD and other lung conditions could be provided by community diagnostic centres (CDCs), as these are rolled out further across England.⁹⁷

Targeted Lung Health Checks and case finding can also address inequalities by focusing on areas of deprivation, where COPD prevalence is lower than expected.

- Due to the increased burden of COPD for people who are poorer, poorer people with COPD may need focused efforts to support implementation of the five fundamentals, thereby helping them to manage their condition and to reduce exacerbations.

This will require equal distribution of and access to healthcare professionals in the areas that are in greatest need, particularly for respiratory skills and training, diagnostic tests such as spirometry, and treatments such as smoking cessation and other specialist respiratory services.

- We urgently need an NHS Workforce Strategy to address the capacity and capability gaps in primary care, and to adequately resource community and secondary care services which have been overwhelmed by COVID-19.

Health services should work with local authorities across integrated care systems to reduce risk factors such as poor housing, mould, smoking rates and pollution near homes, schools and workplaces. This will help to promote good lung health across all populations.

As indicated above, our recommendation on case finding by GPs in Chapter One also seeks to address this issue.

Smoking cessation:

- **Local authorities should receive adequate funding so that all smokers wanting to quit receive adequate support to do so, wherever they live in the UK.**
- Targeted and tailored efforts should be made to encourage smokers in disadvantaged and lesser-seen communities to consider seeking treatment.
- **We recommend that the recommendations of the Khan review are implemented in full,⁹⁸ including the levy on the tobacco industry, to ensure that local authorities have adequate funding for smoking cessation services for all who would like to access them.**
- We recommend the Ottawa Model⁹⁹ for smoking cessation within in-patient settings in hospitals, and use of the Very Brief Advice¹⁰⁰ approach in primary care.¹⁰¹
- **Smoking cessation should be made a core part of undergraduate and postgraduate medical training.**

Air pollution:

- **Through a health awareness campaign, raise awareness amongst people with COPD about the availability of air pollution alerts so they're able to protect themselves from harm.** Government should work with institutions including the NHS, local councils, charities, non-governmental organisations (NGOs) and schools to increase the number of people using alerts and reach more at-risk groups.
- **Amend clinical teaching guidelines and work closely with the health services to ensure healthcare professionals provide sufficient advice on air pollution to people living with lung conditions,** as recommended by the Coroner in the Prevention of Future Deaths report for Ella Adoo Kissi-Debrah.¹⁰²

Conclusion

These results are another difficult read, and people with COPD are being let down by healthcare systems across the UK. Policymakers responsible for healthcare delivery have a key role to play to ensure the effective implementation of existing policy in this area, and to develop key areas, such as investment in research and Targeted Lung Health Checks, further. This could improve care for people with COPD and, more broadly, lung health for everyone UK-wide.

Problems with diagnosis are particularly concerning – even getting a diagnosis of COPD is a difficult milestone, and up to two thirds of those with COPD are undiagnosed.¹⁰³ Diagnosis of COPD needs to be faster and more accurate. We want to see an urgent increase in availability of spirometry across the system, to at least pre-pandemic levels. Central support for solutions to achieve this is required across the UK.

Asthma + Lung UK will act to raise awareness of key symptoms, such as breathlessness, through our campaigning activity.

We want to see a breathlessness pathway implemented in every UK nation to help achieve faster diagnosis for those presenting with these symptoms.

Care provided for people with COPD is uneven. Some groups of people with COPD (such as those who are poorer) are particularly struggling with higher levels of symptoms, exacerbation rates (or flare-ups), and with less support from the NHS.

The stories in this report demonstrate the impact of COPD on people with the condition. Outcomes for people with COPD in the UK are the worst in Western Europe. More needs to be done to tackle this urgently, and to address the disproportionate impact of inequalities on the poorest people with COPD.

We hope to see the promotion of lung health included in all inequalities strategies and prioritised for implementation within all national health strategies, such as the refreshed NHS Long Term Plan and the NHS Workforce Strategy.

In summary, we are calling for governments and health services across all four nations of the UK to:

- **Implement a pre-diagnosis breathlessness pathway,^{xv} to improve the speed and accuracy of diagnosis within primary care.**
- **Prioritise urgently increasing the capacity for timely, quality assured spirometry across the system, particularly in primary care, so that this is available universally.**
- **Run a public awareness campaign on key symptoms, such as breathlessness,** to encourage people to seek diagnosis and treatment.
- **Include lung health in all inequalities strategies.**

^{xv} Modelled on the Diagnostic Pathway Support Tool, developed in England for adults presenting with chronic persistent breathlessness of more than 8 weeks' duration.

- **Ensure timely case finding amongst high-risk groups** (such as smokers, people experiencing homelessness, who are poorer or in a high-risk occupation) to identify COPD and other lung conditions, so that these can be treated sooner.
- **Ensure services maximise the opportunities provided by Targeted Lung Health Checks**, to make sure that evidence of conditions other than lung cancer is not ignored.
- **Address inequalities** through both case finding and Targeted Lung Health Checks by focusing on areas of deprivation, where COPD prevalence is lower than expected.
- **Prioritise lung health in the implementation of all national health strategies**, such as the refreshed NHS Long Term Plan.
- **Smoking cessation:** the Government must move swiftly to implement the recommendations of the Khan review:¹⁰⁴ making smoking obsolete immediately, including adequate funding (from a levy on the tobacco industry) for local authorities to support smokers wishing to quit to do so.
- **Urgently develop an NHS Workforce Strategy** to address the capacity and capability gaps in primary care, and to adequately resource community and secondary care services which have been overwhelmed by COVID-19.
- **Air pollution:** raise awareness amongst people with COPD about the availability of air pollution alerts, so they're able to better protect themselves from harm.
- **Amend clinical teaching guidelines** and work closely with the health services to ensure healthcare professionals provide sufficient advice on air pollution to people living with lung conditions.
- Invest in further **research and innovation** for COPD.
- **National Asthma and COPD Audit Programme (NACAP):** we also recommend engaging with quality improvement programmes and resources through NACAP, where high-quality local data on the care people with COPD are receiving would be useful.

About the survey

The survey this report is based on was conducted by Asthma + Lung UK^{xvi} from January 2022 – April 2022. The survey was conducted online, and responses were encouraged via both paid and organic social media posts on Asthma + Lung UK channels, emails to our supporter base and promotion on the Asthma + Lung UK website. After data cleaning (removing duplicate and incomplete responses), the survey received 6,551 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 and Rachel Warren.

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

xvi In January and February, the survey was promoted under British Lung Foundation branding.

Appendices

Appendix A: References

1. Health Foundation, REAL centre. 2021. *Direct and Indirect Health Impacts of COVID-19 in England: Short Paper*. Department of Health and Social Care. Accessed [here](#) (August 2022).
2. National Institute for Health and Care Excellence (NICE). 2022. *Chronic obstructive pulmonary disease in over 16s: non-pharmacological management and use of inhaled therapies*. NICE. Accessed [here](#) (August 2022).
3. Philip K, Gaduzo S, Rogers J, et al. 2019. *Patient experience of COPD care: outcomes from the British Lung Foundation Patient Passport*. *BMJ Open Respir Res*. Accessed [here](#) (August 2022).
4. British Lung Foundation. 2022. *Chronic obstructive pulmonary disease (COPD) statistics: Numbers of people diagnosed with COPD*. British Lung Foundation. Accessed [here](#) (September 2022).
5. Ibid.
6. Philip K, Gaduzo S, Rogers J, et al. 2019. *Patient experience of COPD care: outcomes from the British Lung Foundation Patient Passport*. *BMJ Open Respir Res*. Accessed [here](#) (August 2022).
7. Asthma + Lung UK. 2022. *COPD Patient Passport*. Asthma + Lung UK. Accessed [here](#) (August 2022).
8. British Lung Foundation. 2021. *Failing on the fundamentals: Insights from those living with chronic obstructive pulmonary disease (COPD) around the UK*. British Lung Foundation. Accessed [here](#) (August 2022).
9. Nacul L, Soljak M, Samarasundera E, et al. 2011. *COPD in England: a comparison of expected, model-based prevalence and observed prevalence from general practice data*. *J Public Health*. Accessed [here](#) (September 2022).
10. National Institute for Health and Care Excellence (NICE). 2016. *Chronic obstructive pulmonary disease in adults*. NICE. Accessed [here](#) (August 2022).
11. Ibid.
12. National Institute for Health and Care Excellence (NICE). 2022. *Chronic obstructive pulmonary disease in over 16s: non-pharmacological management and use of inhaled therapies*. NICE. Accessed [here](#) (August 2022).
13. Association for Respiratory Technology & Physiology (ARTP) and Primary Care Respiratory Society (PCRS). 2021. *Risk minimisation in spirometry restart. Spirometry in Primary Care: Guidance on reinstating spirometry in England*. ARTP. Accessed [here](#) (September 2022). P. 5.
14. National Institute for Health and Care Excellence (NICE). 2022. *Chronic obstructive pulmonary disease in over 16s: non-pharmacological management and use of inhaled therapies*. NICE. Accessed [here](#) (August 2022).
15. British Lung Foundation. 2021. *Failing on the fundamentals: Insights from those living with chronic obstructive pulmonary disease (COPD) around the UK*. British Lung Foundation. Accessed [here](#) (October 2022). PP. 14-15.
16. Williams PJ, Cumella A, Philip KEJ, et al. 2022. *Smoking and socioeconomic factors linked to acute exacerbations of COPD: analysis from an Asthma + Lung UK survey*. *BMJ Open Respir Res*. Accessed [here](#) (August 2022).
17. Khan J. 2022. *The Khan Review: Making Smoking obsolete. Independent review into smokefree 2030 policies*. Office for Health Improvement and Disparities. Accessed [here](#) (August 2022).

18. See Scottish Government. 2021. *Respiratory care – action plan: 2021 to 2026*. Scottish Government. Accessed **here** (August 2022).
19. See Welsh Government. 2018. *Respiratory health delivery plan 2018 to 2020*. Welsh Government. Accessed **here** (August 2022).
20. See National Health Service (NHS). 2019. *NHS Long Term Plan*. NHS. Accessed **here** (August 2022).
21. UK National Screening Committee (UK NSC). 2022. *UK NSC recommends introduction of targeted lung cancer screening*. UK NSC. Accessed **here** (October 2022).
22. National Institute for Health and Care Excellence (NICE). 2022. *Chronic obstructive pulmonary disease in over 16s: diagnosis and management*. NICE Guideline [NG115]. NICE. Accessed **here** (August 2022).
23. National Institute for Health and Care Excellence (NICE). 2022. *Chronic obstructive pulmonary disease in over 16s: non-pharmacological management and use of inhaled therapies*. NICE. Accessed **here** (August 2022).
24. Khan J. 2022. *The Khan Review: Making Smoking obsolete. Independent review into smokefree 2030 policies*. Office for Health Improvement and Disparities. Accessed **here** (August 2022).
25. Asthma + Lung UK. 2022. *COPD (chronic obstructive pulmonary disease)*. Asthma + Lung UK. Accessed **here** (September 2022).
26. Ibid.
27. National Institute for Health and Care Excellence (NICE). 2022. *Chronic obstructive pulmonary disease in over 16s: non-pharmacological management and use of inhaled therapies*. NICE. Accessed **here** (August 2022).
28. Association for Respiratory Technology & Physiology (ARTP) and Primary Care Respiratory Society (PCRS). 2021. *Risk minimisation in spirometry restart. Spirometry in Primary Care: Guidance on reinstating spirometry in England*. ARTP. Accessed **here** (September 2022). P. 5.
29. British Lung Foundation. 2021. *Failing on the fundamentals: Insights from those living with chronic obstructive pulmonary disease (COPD) around the UK*. British Lung Foundation. Accessed **here** (August 2022). PP. 14-15.
30. National Institute for Health and Care Excellence (NICE). 2022. *Chronic obstructive pulmonary disease in over 16s: non-pharmacological management and use of inhaled therapies*. NICE. Accessed **here** (August 2022).
31. Williams PJ, Cumella A, Philip KEJ, et al. 2022. *Smoking and socioeconomic factors linked to acute exacerbations of COPD: analysis from an Asthma + Lung UK survey*. *BMJ Open Respir Res*. Accessed **here** (August 2022).
32. British Lung Foundation. 2021. *Failing on the fundamentals: Insights from those living with chronic obstructive pulmonary disease (COPD) around the UK*. British Lung Foundation. Accessed **here** (August 2022).
33. National Institute for Health and Care Excellence (NICE). 2016. *Chronic obstructive pulmonary disease in adults*. NICE. Accessed **here** (August 2022).
34. Jones RCM, Price D, Ryan D, et al. 2014. *Opportunities to diagnose chronic obstructive pulmonary disease in routine care in the UK: a retrospective study of a clinical cohort*. *The Lancet*. Accessed **here** (September 2022).
35. National Institute for Health and Care Excellence (NICE). 2016. *Chronic obstructive pulmonary disease in adults*. NICE. Accessed **here** (August 2022).
36. National Institute for Health and Care Excellence (NICE). 2022. *Diagnosis of chronic obstructive pulmonary disease*. NICE. Accessed **here** (August 2022).
37. Department for Health and Social Care and the Office for National Statistics. 2021. *Direct and Indirect health impacts of COVID-19 in England – short paper*. Department for Health and Social Care. Accessed **here** (August 2022).
38. Association for Respiratory Technology & Physiology (ARTP) and Primary Care Respiratory Society (PCRS). 2021. *Risk minimisation in spirometry restart. Spirometry in Primary Care: Guidance on reinstating spirometry in England*. ARTP. Accessed **here** (September 2022). P. 5.
39. Ibid.
40. British Thoracic Society (BTS). 2022. *BTS publishes new report – A respiratory workforce for the future*. BTS. Accessed **here** (October 2022).
41. National Institute for Health and Care Excellence (NICE). 2016. *Chronic obstructive pulmonary disease in adults*. NICE. Accessed **here** (August 2022).

42. Whittaker H, Rubino A, Müllerová H, et al. 2022. *Frequency and Severity of Exacerbations of COPD Associated with Future Risk of Exacerbations and Mortality: A UK Routine Health Care Data Study*. *Int J Chron Obstruct Pulmon Dis*. Accessed **here** (August 2022).
43. Tudor Hart J. 1971. *The Inverse Care Law*. *The Lancet*. Accessed **here** (September 2022).
44. Asthma + Lung UK. 2022. *Listen to your lungs*. Accessed **here** (September 2022).
45. Martinez FJ, Calverley PMA, Goehring U-M et al. 2015. *Effect of roflumilast on exacerbations in patients with severe chronic obstructive pulmonary disease uncontrolled by combination therapy (REACT): a multicentre randomised controlled trial*. *The Lancet*. In note 46 below.
46. Stolz D, Mkorombindo T, Schumann DM, et al. 2022. *Towards the elimination of chronic obstructive pulmonary disease: a Lancet commission*. *The Lancet*. Accessed **here** (October 2022). P. 953.
47. Woolnough S. 2022. *Shaping the future of Respiratory Research and Innovation*. Asthma + Lung UK. Accessed **here** (October 2022).
48. National Institute for Health and Care Excellence (NICE). 2022. *Chronic obstructive pulmonary disease in over 16s: diagnosis and management*. *NICE Guideline [NG115]*. NICE. Accessed **here** (August 2022).
49. Hopkinson NS, Molyneux A, Pink J, et al. 2019. *Chronic obstructive pulmonary disease: diagnosis and management: summary of updated NICE guidance*. *BMJ*. Accessed **here** (September 2022).
50. Sennett K. 2019. *Key learning points: NICE chronic obstructive pulmonary disease (COPD). Guidelines in practice*. Accessed **here** (September 2022).
51. The Primary Care Respiratory Society (PRCS). 2021. *MRC Dyspnoea Scale*. PCRS. Accessed **here** (August 2022).
52. National Institute for Health and Care Excellence (NICE). 2022. *Chronic obstructive pulmonary disease in over 16s: non-pharmacological management and use of inhaled therapies*. NICE. Accessed **here** (August 2022).
53. Ibid.
54. Strassman R, Bausch B, Spaar JK, et al. 2009. *Smoking cessation interventions in COPD: a network meta-analysis of randomised trials*. *European Respiratory Journal*. Accessed **here** (September 2022).
55. Asthma + Lung UK. 2022. *Clearing the Smoke: Levelling up health by stamping out tobacco*. Asthma + Lung UK. Accessed **here** (August 2022).
56. Asthma + Lung UK. 2020. *Keeping well in the cold: what you can do*. Asthma + Lung UK. Accessed **here** (September 2022).
57. Taskforce for Lung Health. *Keeping Lungs Healthy: flu vaccinations*. Taskforce for Lung Health. Accessed **here** (September 2022).
58. Halpin D. 2022. *GOLD strategy in 2022: key updates for primary care*. *Guidelines in Practice*. Accessed **here** (October 2022).
59. Asthma + Lung UK. 2020. *Keeping active with a lung condition*. Asthma + Lung UK. Accessed **here** (September 2022).
60. NHS Digital. 2022. *Quality and Outcomes Framework 2021–22*. NHS Digital. Accessed **here** (September 2022).
61. British Lung Foundation. 2021. *Failing on the fundamentals: Insights from those living with chronic obstructive pulmonary disease (COPD) around the UK*. British Lung Foundation. Accessed **here** (August 2022). P. 19.
62. Ibid.
63. British Lung Foundation. 2021. *Failing on the fundamentals: Insights from those living with chronic obstructive pulmonary disease (COPD) around the UK*. British Lung Foundation. Accessed **here** (August 2022). PP. 14-15.
64. Whittaker H, Rubino A, Müllerová H, et al. 2022. *Frequency and Severity of Exacerbations of COPD Associated with Future Risk of Exacerbations and Mortality: A UK Routine Health Care Data Study*. *Int J Chron Obstruct Pulmon Dis*. Accessed **here** (August 2022).
65. National Institute for Health and Care Excellence (NICE). 2022. *Chronic obstructive pulmonary disease in over 16s: diagnosis and management*. *NICE Guideline [NG115]*. NICE. Accessed **here** (August 2022).
66. National Health Service (NHS). 2019. *NHS Long Term Plan*. NHS. Accessed **here** (August 2022).
67. Scottish Government. 2021. *Respiratory care – action plan: 2021 to 2026*. Scottish Government. Accessed **here** (August 2022).

68. Welsh Government. 2018. *Respiratory health delivery plan 2018 to 2020*. Welsh Government. Accessed [here](#) (August 2022).
69. Marmot M. 2010. *Fair Society, Healthy Lives. The Marmot Review. Strategic Review of Health Inequalities in England post-2010*. The Marmot Review. Accessed [here](#) (September 2022). P. 17.
70. Ibid.
71. Eurostat. 2021. *Glossary: Material deprivation*. Eurostat. Accessed [here](#) (September 2022).
72. Williams PJ, Cumella A, Philip KEJ, et al. 2022. *Smoking and socioeconomic factors linked to acute exacerbations of COPD: analysis from an Asthma + Lung UK survey*. *BMJ Open Respir Res*. Accessed [here](#) (August 2022).
73. National Institute for Health and Care Excellence (NICE). 2022. *Chronic obstructive pulmonary disease in over 16s: non-pharmacological management and use of inhaled therapies*. NICE. Accessed [here](#) (August 2022).
74. Asthma + Lung UK. 2022. *Managing COPD flare-ups*. Asthma + Lung UK. Accessed [here](#) (September 2022).
75. Asthma + Lung UK. 2022. *Clearing the Smoke: Levelling up health by stamping out tobacco*. Asthma + Lung UK. Accessed [here](#) (August 2022).
76. Asthma + Lung UK. 2022. *Levelling up Lung Health: How improving lung health will achieve levelling up by delivering a healthier, fairer society*. Asthma + Lung UK. Accessed [here](#) (August 2022).
77. Williams PJ, Cumella A, Philip KEJ, et al. 2022. *Smoking and socioeconomic factors linked to acute exacerbations of COPD: analysis from an Asthma + Lung UK survey*. *BMJ Open Respir Res*. Accessed [here](#) (August 2022).
78. British Lung Foundation. 2016. *The Battle for Breath – the impact of lung disease in the UK*. British Lung Foundation. Accessed [here](#) (August 2022). In note 79 below.
79. Asthma UK and British Lung Foundation. 2021. *The Invisible Threat: how we can protect people from air pollution and create a fairer, healthier society*. Asthma UK and British Lung Foundation. Accessed [here](#) (August 2022). P. 16.
80. Philip K, Gaduzo S, Rogers J, et al. 2019. *Patient experience of COPD care: outcomes from the British Lung Foundation Patient Passport*. *BMJ Open Respir Res*. Accessed [here](#) (August 2022).
81. Khan J. 2022. *The Khan Review: Making Smoking obsolete. Independent review into smokefree 2030 policies*. Office for Health Improvement and Disparities. Accessed [here](#) (August 2022).
82. Asthma + Lung UK. 2022. *Clearing the Smoke: Levelling up health by stamping out tobacco*. Asthma + Lung UK. Accessed [here](#) (August 2022).
83. Asthma + Lung UK. 2022. *Clearing the Smoke: Levelling up health by stamping out tobacco*. Asthma + Lung UK. Accessed [here](#) (August 2022). P. 5.
84. Third Force News (TFN). 2020. *Scotland set to miss “smoke free” target*. TFN. Accessed [here](#) (September 2022).
85. Welsh Government. 2022. *A smoke-free Wales: Our long-term tobacco control strategy*. Welsh Government. Accessed [here](#) (August 2022).
86. Welsh Government. 2022. *Towards a smoke-free Wales delivery plan 2022 to 2024*. Welsh Government. Accessed [here](#) (August 2022).
87. Scottish Government. 2018. *Raising Scotland’s tobacco-free generation: our tobacco control plan 2018*. Scottish Government. Accessed [here](#) (August 2022).
88. Department of Health, Northern Ireland. 2020. *Mid term Review Tobacco Control Strategy*. Department of Health. Accessed [here](#) (August 2022).
89. Doiron D, de Hoogh K, Probst-Hensch N, et al. 2019. *Air pollution, lung function and COPD: results from the population-based UK Biobank study*. *European Respiratory Journal*. Accessed [here](#) (September 2022).
90. Asthma UK and British Lung Foundation. 2021. *The Invisible Threat: how we can protect people from air pollution and create a fairer, healthier society*. Asthma UK and British Lung Foundation. Accessed [here](#) (August 2022). P. 15.
91. Department for Environment Food & Rural Affairs. 2017. *Air Quality A Briefing for Directors of Public Health*. Department for Environment Food & Rural Affairs. Accessed [here](#) (August 2022). In note 93 below.

92. Walker G, Mitchell G, Pearce J, et al. 2017. *Pollution and inequality. (In Annual Report of the Chief Medical Officer)*. Department of Health and Social Care. Accessed [here](#) (August 2022). In note 93 below.
93. Asthma UK and British Lung Foundation. 2021. *The Invisible Threat: how we can protect people from air pollution and create a fairer, healthier society*. Asthma UK and British Lung Foundation. Accessed [here](#) (August 2022). PP. 15-16.
94. Department of Health and Social Care. 2018. *Chief Medical Officer annual report 2017: health impacts of all pollution – what do we know?* Department of Health and Social Care. Accessed [here](#) (August 2022). In note 95 below.
95. Asthma UK and British Lung Foundation. 2021. *The Invisible Threat: how we can protect people from air pollution and create a fairer, healthier society*. Asthma UK and British Lung Foundation. Accessed [here](#) (August 2022). P. 16.
96. UK National Screening Committee (UK NSC). 2022. *UK NSC recommends introduction of targeted lung cancer screening*. UK NSC. Accessed [here](#) (October 2022).
97. Warren R. 2022. *Key to faster diagnosis for lung conditions in the NHS*. Open Access Government. Accessed [here](#) (October 2022).
98. Khan J. 2022. *The Khan Review: Making Smoking obsolete. Independent review into smokefree 2030 policies*. Office for Health Improvement and Disparities. Accessed [here](#) (August 2022).
99. University of Ottawa Heart Institute. 2022. *Ottawa Model for Smoking Cessation*. University of Ottawa Heart Institute. Accessed [here](#) (August 2022).
100. Asthma + Lung UK. 2022. *Clearing the Smoke: Levelling up health by stamping out tobacco*. Asthma + Lung UK. Accessed [here](#) (August 2022). P. 26.
101. British Lung Foundation. 2021. *Failing on the fundamentals: Insights from those living with chronic obstructive pulmonary disease (COPD) around the UK*. British Lung Foundation. Accessed [here](#) (August 2022). PP. 5, 19.
102. Barlow P. 2021. *Regulation 28: Report to Prevent Future Deaths (1)*. Courts and Tribunals Judiciary. Available [here](#) (May 2022).
103. National Institute for Health and Care Excellence (NICE). 2016. *Chronic obstructive pulmonary disease in adults*. NICE. Accessed [here](#) (August 2022).
104. Khan J. 2022. *The Khan Review: Making Smoking obsolete. Independent review into smokefree 2030 policies*. Office for Health Improvement and Disparities. Accessed [here](#) (August 2022).

Appendix B: Survey questions

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

- 1) Who are you completing this survey for?
 - Yourself
 - Someone you care for
 - Other
- 2) What is your age?
[numerical value]
- 3) Which of the following best describes you?
 - Female
 - Male
 - Non-binary
 - Prefer not to say
 - Other (Please describe)
- 4) What nation do you live in?
 - England
 - Northern Ireland
 - Scotland
 - Wales
- 5) [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
- 6) [for respondents in East Midlands] Which part of the East Midlands do you live in?
 - Derbyshire and Nottinghamshire
 - Leicestershire, Rutland and Northamptonshire
 - Lincolnshire
- 7) [for respondents in the East of England] Which part of the East of England do you live in?
 - Bedfordshire and Hertfordshire
 - East Anglia
 - Essex
- 8) [for respondents in North East] Which part of the North East do you live in?
 - Tees Valley and Durham
 - Northumberland and Tyne and Wear
- 9) [for respondents in North West] Which part of the North West do you live in?
 - Cumbria
 - Cheshire
 - Greater Manchester
 - Lancashire
 - Merseyside
- 10) [for respondents in South East] Which part of the South East do you live in?
 - Berkshire, Buckinghamshire and Oxfordshire
 - Surrey, East Sussex and West Sussex
 - Hampshire and the Isle of Wight
 - Kent
- 11) [for respondents in South West] Which part of the South West do you live in?
 - Cornwall and the Isles of Scilly
 - Devon
 - Dorset and Somerset
 - Gloucestershire, Wiltshire and the Bristol/Bath area
- 12) [for respondents in West Midlands] Which part of the West Midlands do you live in?
 - Herefordshire, Worcestershire and Warwickshire
 - Shropshire and Staffordshire
 - West Midlands
- 13) [for respondents in Yorkshire and the Humber] Which part of Yorkshire and the Humber do you live in?
 - East Riding and North Lincolnshire
 - North Yorkshire
 - South Yorkshire
 - West Yorkshire
- 14) [for respondents in Scotland] Which region do you live in?
 - Central Scotland
 - Glasgow
 - Highlands and Islands
 - Lothian
 - Mid Scotland and Fife
 - North East Scotland
 - South Scotland
 - West Scotland

- 15) [for respondents in Wales] Which health board area do you live in?
- Aneurin Bevan
 - Betsi Cadwaladr
 - Cardiff and Vale
 - Cwm Taf Morgannwg
 - Hywel Dda
 - Powys
 - Swansea Bay
- 16) [for respondents in Northern Ireland] Which health board area do you live in?
- Belfast
 - Northern
 - South Eastern
 - Southern
 - Western
- 17) Which one of the following best describes your ethnic group or background?
- White
 - Mixed or multiple ethnic groups
 - Asian or Asian British
 - Black, African, Black British or Caribbean
 - Other
- 18) [white] Which one of the following best describes your ethnic group or background?
- English/Welsh/Scottish/Northern Irish/British
 - Irish
 - Gypsy or Irish Traveller
 - Other (Please describe)
- 19) [Mixed or multiple ethnic groups] Which one of the following best describes your ethnic group or background?
- White and Black Caribbean
 - White and Black African
 - White and Asian
 - Other (Please describe)
- 20) [Asian or Asian British] Which one of the following best describes your ethnic group or background?
- Indian
 - Pakistani
 - Bangladeshi
 - Chinese
 - Other (Please describe)
- 21) [Black, African, Black British or Caribbean] Which one of the following best describes your ethnic group or background?
- African
 - Caribbean
 - Other (Please describe)
- 22) [Other] Which one of the following best describes your ethnic group or background?
- Arab
 - Other (Please describe)
- 23) What is the total annual income of your household (before tax and deductions, but including benefits/allowances)? *We are asking this to find out how care for COPD varies for people on different incomes.*
- Below £20,000
 - £20,000-£30,000
 - £30,001-£40,000
 - £40,001-£70,000
 - Above £70,000
 - Rather not say
- 24) Which of the following are you NOT able to afford? *[multiple choice]*
- Mortgage or rent payments, utility bills (such as electricity and water) or other loan payments
 - A car
 - Unexpected financial expense (e.g., your boiler breaks, and you can't afford to replace it)
 - Heating to keep the home adequately warm
 - A washing machine
 - A TV
 - A telephone (including mobile telephone)
 - A meal with meat, chicken, fish or vegetarian equivalent every other day
 - One week's holiday away from home
 - I can afford all of the above
 - Rather not say
- 25) 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

26) How old were you when you first noticed symptoms of COPD?

Common symptoms include increasing breathlessness, a persistent chesty cough with phlegm that does not go away, frequent chest infections and persistent wheezing.

[numerical value]

27) 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

28) How long did you have to wait between talking about your COPD symptoms with your GP or healthcare professional, to receiving a formal COPD 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

29) How old were you when you were diagnosed with COPD?

- [numerical value]

30) 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

31) 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

32) 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

33) After your diagnosis, did you feel you had enough knowledge and support to manage your COPD?

- Yes
- No
- Don't remember

34) 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

35) 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

36) Do you smoke?

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

- 37) [for those who smoke] In the past 12 months, have you been offered treatment and support to stop smoking?
- Yes
 - No
- 38) In the past 12 months, have you had a flu jab?
- Yes
 - No
 - Don't know
- 39) 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
- 40) 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
- 41) [if no to above] Have you ever been offered the chance to do pulmonary rehabilitation?
- Yes
 - No
- 42) Do you currently have a COPD self-management plan?
- Yes
 - No
 - Don't know
- 43) [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
- 44) 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
- 45) Do you know what your medicines and inhalers for your COPD are for, and when to take them?
- Yes, I know this about all of them
 - Yes, I know this about some of them
 - No
 - Not sure
- 46) 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
- [type number]
- 47) Do you know what to do if your COPD symptoms get worse (you have a flare-up)?
- Yes
 - No
- 48) How has the COVID-19 pandemic affected your COPD care?
- It has made it much worse
 - It has made it a bit worse
 - It is about the same
 - It has made it better
 - It has made it much better
 - I have been diagnosed with COPD since the start of the pandemic, so can't compare it
- 49) Is your COPD affected by air pollution?
- Yes – often
 - Yes – sometimes
 - No
 - Don't know
- 50) [for those who say it is affected by air pollution] In what ways does air pollution affect you?
- Feeling more breathless
 - Having to use your medication more
 - Not being able to walk as far
 - Not exercising
 - Not leaving house
 - Closing windows
 - Not seeing family and friends
 - Missing medical appointments
 - Adding to anxiety
 - Other

Appendix C: Data tables

This is the data used in the report. The data is presented in order of appearance in the report. For further information about this data, please email data@asthmaandlung.org.uk.

Table 1: Time between first noticing potential COPD symptoms and receiving a diagnosis:

Number of years	Respondents	Percentage
0	2579	41.9%
1	998	16.2%
2	676	11.0%
3	328	5.3%
4	189	3.1%
5	335	5.4%
6	113	1.8%
7	76	1.2%
8	56	0.9%
9	43	0.7%
10	119	1.9%
11–20	231	3.8%
21+	414	6.7%
All respondents	6157	

Table 2: Provision of the five fundamentals of COPD care, 2021–2022

	Number of respondents		Percentage	
	2021	2022	2021	2022
Received	1979	1142	24.5%	17.6%
Did not receive	6086	5345	75.5%	82.4%
All respondents	8065	6487	100.0%	100.0%

Table 3: Barriers to receiving a COPD diagnosis (those who were diagnosed with COPD in the past 2 years, or waiting for a diagnosis)

Barrier	Number	Percentage
Not knowing what the signs of potential COPD were	307	34.0%
Difficulty in getting appointments	231	25.6%
My GP thought I had a chest infection or cough at first	211	23.3%
Diagnostic tests not being available	189	20.9%
Initial misdiagnosis	146	16.2%
I do not recall there being any barriers	130	14.4%
Concern that I might have lung cancer	98	10.8%
I was sent away by my GP when I first mentioned it	61	6.7%
Not wanting to know if I had COPD	60	6.6%
Other [free text]	13	1.4%
All respondents	904	

Table 4: Respondents receiving tests as part of their routine care, in the past 12 months

Test	Respondents	Percentage
Spirometry testing	1409	21.5%
A peak flow reading	1794	27.4%
A chest x-ray	2021	30.9%
A lung volume test	966	14.7%
A CT scan	1001	15.3%
Other [free text]	73	1.1%
	6551	

Table 5: Provision of the individual elements of the five fundamentals of COPD care

Measure	Answer	Number of respondents	Percentage
Offered smoking cessation support	Yes	667	54.3%
	No	562	45.7%
	All respondents	1229	
Offered flu vaccine	Yes	5791	89.4%
	No	677	10.5%
	Don't know	7	0.1%
	All respondents	6475	
Had pneumonia vaccine	Yes	4348	67.1%
	No	1850	28.5%
	Don't know	286	4.4%
	All respondents	6484	
Had/offered pulmonary rehabilitation	Yes	3139	48.4%
	No	3349	51.6%
	All respondents	6488	100.0%
Currently have a self-management plan	Yes	2106	32.4%
	No	3567	54.8%
	I don't know	831	12.8%
	All respondents	6504	
Co-developed their plan	Yes	1209	58.0%
	No	469	22.5%
	I can't remember	406	19.5%
	All respondents	2084	
Optimise treatment for comorbidities	Yes	2082	32.1%
	No	3606	55.6%
	I don't have any other long-term medical conditions	502	7.7%
	Don't know	295	4.5%
	All respondents	6485	

Table 6: Provision of the five fundamentals of COPD care, by nation

	Number of respondents			Percentage	
	Received 5F	Did not receive 5F	All respondents	Received	Did not receive
England	988	4395	5383	18.4%	81.6%
Northern Ireland	15	109	124	12.1%	87.9%
Scotland	88	519	607	14.5%	85.5%
Wales	51	322	373	13.7%	86.3%
UK	1142	5345	6487	17.6%	82.4%

Table 7: Length of wait before talking about COPD symptoms with a healthcare professional

Time waited	Respondents	Percentage
One month or less	603	9.3%
1–2 months	452	7.0%
3–6 months	781	12.1%
6 months – a year	1284	19.8%
A year – two years	1246	19.2%
More than two years	1090	16.8%
I don't remember	1022	15.8%
All respondents	6478	

Table 8: Activities done during COPD diagnosis

Activity	Respondents	Percentage
I was asked about smoking	586	72.9%
A chest x-ray	518	64.4%
Spirometry testing	407	50.6%
A peak flow reading	404	50.2%
Blood tests	333	41.4%
A CT scan of my chest	325	40.4%
We had a discussion about my symptoms	304	37.8%
We had a discussion about smoking	216	26.9%
We had a discussion about my work history	139	17.3%
I was asked about any problems with my chest during childhood	125	15.5%
I don't remember	18	2.2%
None of the above	14	1.7%
Total	804	

Table 9: Provision of supportive material post-diagnosis

Material to support managing COPD provided?	Respondents	Percentage
Yes	245	30.7%
No	487	61.0%
Don't remember	66	8.3%
Total	798	

Table 10: Provision of five fundamentals care across England

Area	Yes	No	All respondents	Percentage receiving 5F
Bedfordshire and Hertfordshire	28	120	148	18.9%
Berkshire, Buckinghamshire and Oxfordshire	28	133	161	17.4%
Cheshire	13	97	110	11.8%
Cornwall and the Isles of Scilly	13	78	91	14.3%
Cumbria	10	48	58	17.2%
Derbyshire and Nottinghamshire	50	212	262	19.1%
Devon	36	137	173	20.8%
Dorset and Somerset	23	159	182	12.6%
East Anglia	66	306	372	17.7%
East Riding and North Lincolnshire	15	73	88	17.0%
Essex	39	122	161	24.2%
Gloucestershire, Wiltshire and the Bristol/Bath area	49	162	211	23.2%
Greater Manchester	35	154	189	18.5%
Hampshire and the Isle of Wight	41	194	235	17.4%
Herefordshire, Worcestershire and Warwickshire	30	89	119	25.2%
Kent	46	189	235	19.6%
Lancashire	32	175	207	15.5%
Leicestershire, Rutland and Northamptonshire	38	141	179	21.2%
Lincolnshire	16	92	108	14.8%
London	65	287	352	18.5%
Merseyside	18	97	115	15.7%
North Yorkshire	9	70	79	11.4%
Northumberland and Tyne & Wear	28	141	169	16.6%
Shropshire and Staffordshire	23	114	137	16.8%
South Yorkshire	26	133	159	16.4%
Surrey, East Sussex and West Sussex	73	247	320	22.8%
Tees Valley and Durham	19	102	121	15.7%
West Midlands	32	180	212	15.1%
West Yorkshire	47	172	219	21.5%
All respondents	948	4224	5172	18.3%

Table 11: Exacerbations by level of deprivation

Number of exacerbations	Number of respondents				Percentage			
	No material deprivation	Material deprivation	Severe material deprivation	All respondents	No material deprivation	Material deprivation	Severe material deprivation	All respondents
0	690	53	44	787	19.7%	8.8%	6.9%	16.6%
1	544	72	49	665	15.6%	11.9%	7.7%	14.0%
2	611	87	99	797	17.5%	14.4%	15.5%	16.8%
3	451	85	113	649	12.9%	14.1%	17.7%	13.7%
4	291	81	73	445	8.3%	13.4%	11.4%	9.4%
5+	909	225	260	1394	26.0%	37.3%	40.8%	29.4%
All respondents	3496	603	638	4737				

Table 12: Provision of five fundamentals care, by deprivation level

	Yes	No	All respondents
No material deprivation	696	3020	3716
Material deprivation	90	557	647
Severe material deprivation	101	566	667
All respondents	1153	5380	6533
No material deprivation	18.7%	81.3%	100.0%
Material deprivation	13.9%	86.1%	100.0%
Severe material deprivation	15.1%	84.9%	100.0%

Table 13: Provision of COPD self-management plan, by deprivation level

	Respondents				Percentage			
	No material deprivation	Material deprivation	Severe material deprivation	All respondents	No material deprivation	Material deprivation	Severe material deprivation	All respondents
Yes	1272	173	196	1641	34.3%	26.8%	29.5%	32.7%
No	2016	375	381	2772	54.4%	58.1%	57.4%	55.3%
I don't know	416	97	87	600	11.2%	15.0%	13.1%	12.0%
All respondents	3704	645	664	5013	100.0%	100.0%	100.0%	100.0%

Table 14: Knowledge of COPD medicines, by deprivation level

	Respondents				Percentage			
	No material deprivation	Material deprivation	Severe material deprivation	All respondents	No material deprivation	Material deprivation	Severe material deprivation	All respondents
Yes, I know this about all of them	3021	484	471	3976	82.1%	75.6%	71.0%	79.8%
Yes, I know this about some of them	434	96	119	649	11.8%	15.0%	17.9%	13.0%
No	107	20	39	166	2.9%	3.1%	5.9%	3.3%
Not sure	118	40	34	192	3.2%	6.3%	5.1%	3.9%
	3680	640	663	4983	100.0%	100.0%	100.0%	100.0%

Table 15: Smoking cessation services offered, by deprivation level

	No material deprivation	Material deprivation	Severe material deprivation	All respondents
Yes	349	82	93	524
No	271	77	109	457
All respondents	620	159	202	981
Yes	56.3%	51.6%	46.0%	
No	43.7%	48.4%	54.0%	

Table 16: Air pollution affecting COPD, by deprivation level

	Respondents				Percentage			
	No material deprivation	Material deprivation	Severe material deprivation	All respondents	No material deprivation	Material deprivation	Severe material deprivation	All respondents
Yes – often	919	213	272	1404	25.0%	33.2%	41.0%	28.2%
Yes – sometimes	1519	260	247	2026	41.3%	40.6%	37.3%	40.7%
No	373	45	45	463	10.1%	7.0%	6.8%	9.3%
Don't know	869	123	99	1091	23.6%	19.2%	14.9%	21.9%
All respondents	3680	641	663	4984	100.0%	100.0%	100.0%	100.0%

Table 17: How air pollution affected COPD (for those who told us it did impact their COPD)

Impact	Respondents	Percentage
Feeling more breathless	3923	90.5%
Not being able to walk as far	2587	59.7%
Having to use your medication more	2567	59.2%
Adding to anxiety	1715	39.6%
Not leaving home	1004	23.2%
Closing windows	936	21.6%
Not exercising	759	17.5%
Not seeing family and friends	573	13.2%
Missing medical appointments	213	4.9%
All respondents	4334	

Demographics of survey respondents

Table 18: Age profile of survey respondents

Age band	Number	Percentage
40 or under	17	0.3%
41–55	42	0.6%
46–50	76	1.2%
51–55	418	6.4%
56–60	682	10.4%
61–65	1215	18.5%
66–70	1486	22.7%
71–75	1451	22.1%
76–80	785	12.0%
81–85	238	3.6%
86+	71	1.1%
(blank)	70	1.1%
All respondents	6551	

Table 19: Sex of survey respondents

Sex	Respondents	Percentage
Other	0	0.0%
Prefer not to say	6	0.1%
Non-binary	2	0.0%
Male	2556	39.0%
Female	3903	59.6%
(blank)	84	1.3%
All respondents	6551	

Table 20: Ethnicity of survey respondents

Ethnicity	Respondents	Percentage
Asian or Asian British	23	0.4%
Black, African, Black British or Caribbean	18	0.3%
Mixed	35	0.5%
White	6400	97.7%
Other	10	0.2%
Blank	65	1.0%
All respondents	6486	100.0%

Table 21: Material deprivation level of survey respondents

Deprivation level	Respondents	Percentage
No material deprivation	3716	56.7%
Material deprivation	647	9.9%
Severe material deprivation	667	10.2%
Unknown	1521	23.2%
All respondents	6551	100.0%

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