COPD VOICES

A matter of life and breath

A consultation exercise to understand the needs and insights of people with lived experience of chronic obstructive pulmonary disease (COPD)

April 2025

Written and collated by Sue Thomas and Sarah Mehta

In collaboration with

KING'S College LONDON

Contents

AstraZeneca, GSK and Sanofi have provided grant funding towards the cost of producing this report. They have had no editorial input into, or control over, the content of the report.

Executive summary

Chronic obstructive pulmonary disease (COPD) affects **millions across the UK**, yet people continue to face significant challenges in managing their condition across regions and care systems.

The voices of people with COPD (PwCOPD) and their carers are the cornerstone of this report. Their insights and lived experience have allowed us to build a detailed picture of why COPD matters and what in our health and care systems needs to change.

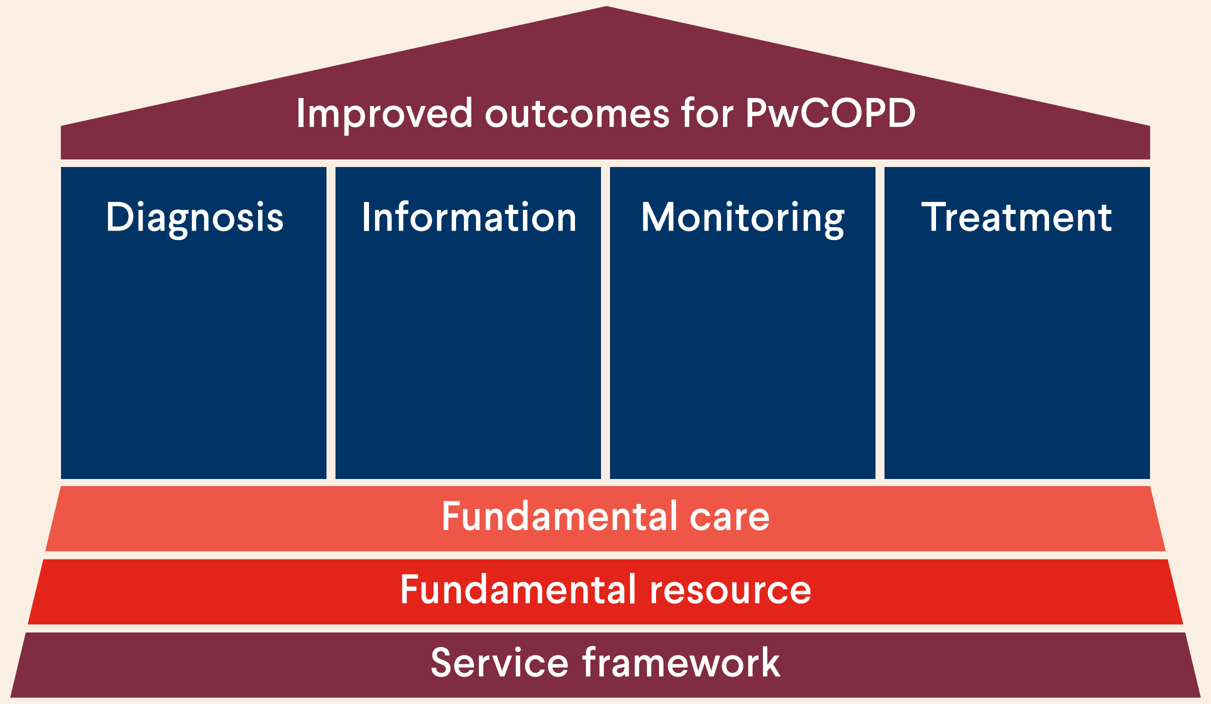
PwCOPD and their carers highlight an overarching problem of **inequitable healthcare access** and an urgent need for more comprehensive, patient-centred care. One of the most critical issues is the **delay in accurate diagnosis** and lack of information provided about COPD. Many PwCOPD report not being diagnosed for years which impacts treatment effectiveness but also leaves them feeling frustrated and unsupported.

PwCOPD consistently report **difficulties accessing services** that are essential to managing their condition, including GP appointments, specialist care and pulmonary rehabilitation. They also experience poor communication between different healthcare providers and inadequate follow-up after hospital discharge.

Many advocate for better **support in managing exacerbations** at home with prompt access to intervention where necessary to reduce hospital admissions and improve quality of life.

As new treatments emerge PwCOPD express a strong interest in participating in research and **accessing innovative treatments**, and ensuring equitable availability across different regions.

Approximately 1 in 10 adults over the age of 40 have COPD in the UK at a cost of £2 billion each year to the NHS[1,2]. Their voices are many, but are distilled here into nine key recommendations. We have translated the improvements PwCOPD would like to see into four fundamental pillars of COPD care.



To promote service transformation, this model provides systems with a set of enablers for delivering optimal COPD care. These are carefully aligned with the strategic goals of the 'three shifts' underway within the NHS[3]. The principal enabler of change is the adoption of **an integrated care pathway approach** to COPD service delivery.

It's time for a coordinated effort to transform COPD services to ensure that PwCOPD receive the support they need to manage their condition effectively and live fuller, healthier lives.

Forewords

Richard EK Russell

Head of Department, Peter Gorer Department of Immunobiology, King's College London, Consultant Respiratory Physician

Mona Bafadhel

NIHR Research Professor, Professor of Respiratory Medicine, King's College London

People living with COPD and their carers have given us their voice. Their message is clear, and their ask is urgent.

For the first time, we have a comprehensive account of their lived experiences, reflected in the recommendations and model of four fundamental pillars of COPD care outlined in this report. A Matter of Life and Breath highlights the health difficulties, inequalities, and inequities faced by people living with COPD. It also sheds light on the immense burden carried by carers, many of whom take on this role voluntarily and without adequate support.

Two key themes emerge from this report—access and information. There is an urgent need to enhance COPD knowledge across all levels of healthcare, including increasing opportunities for patients to participate in clinical research. Where evidence-based therapies already exist, such as pulmonary rehabilitation, vaccinations, and smoking cessation, we must ensure their consistent and effective delivery. At the same time, as new and emerging therapies (such as biologics) continue to advance, we must be prepared to integrate them into care pathways in innovative and equitable ways.

COPD remains a major cause of disability and premature mortality. This report aligns COPD with the broader shifts in the NHS—from analogue to digital, hospital to community, and sickness to prevention.

People living with COPD and their carers do not want us to give up.

They haven't.

And neither should we.

Jim Shannon

MP for Strangford and Chair of the Respiratory Health APPG

COPD remains one of the most pressing public health challenges of our time, affecting millions across the UK. Despite medical advancements, far too many people face delayed diagnoses, inconsistent care, and avoidable hospital admissions. This report, A Matter of Life and Breath, sheds much-needed light on the lived experiences of those battling COPD and highlights the urgent need for systemic improvements in prevention, diagnosis, and long-term management.

The findings make it clear: people with COPD continue to struggle with inequitable access to essential services and inadequate support to manage their condition effectively. As Chair of the All-Party Parliamentary Group (APPG) for Respiratory Health, I am deeply committed to advocating for policies that improve the quality of life for those affected by respiratory diseases. This report is a crucial step in ensuring that the voices of people with COPD and their carers are heard and that their needs are placed at the heart of future healthcare reforms.

A concerning picture emerges—gaps in care, poor communication between services, and an urgent need for a more integrated, patient-centred approach. The cost of inaction is high, not just for individuals living with COPD but for our healthcare system, which bears a £2 billion annual burden due to this condition[2]. The recommendations in this report, including the four fundamental pillars of COPD care, provide a clear roadmap for meaningful change.

I fully support the call for a coordinated effort to reform COPD services. Policymakers, healthcare providers, and patient advocates must work together to ensure that every individual with COPD receives the timely, high-quality care they deserve.

Finally, I commend the authors of this report for their dedication to bringing these issues to light. I urge all stakeholders—policymakers, healthcare professionals, and members of the public—to engage with the insights presented here and to take action. Together, we can transform COPD care in the UK, improve quality of life for thousands, and build a healthcare system that truly meets the needs of those living with COPD.

Why does COPD matter?

Making the case for change

What is COPD?

Chronic obstructive pulmonary disease (COPD) is the name for a group of lung conditions that cause breathing difficulties.

COPD is a common condition that mainly affects middle-aged or older adults who smoke. Many people do not realise they have it. The breathing problems tend to get gradually worse over time and can limit normal activities although treatment can help keep the condition under control.

COPD is an umbrella term for:

- Emphysema: causes damage to the air sacs in the lungs.
- Chronic bronchitis: long-term inflammation of the airways.

The main symptoms of COPD are:

- Shortness of breath particularly during activities.
- Persistent chesty cough with phlegm.
- Frequent chest infections.
- Frequent or persistent wheezing.

Smokers and ex-smokers often think that their symptoms are due to smoking, when in fact this could be the start of COPD.

Air sacs (alveoli) lose their elasticity and shape making it hard to breathe out

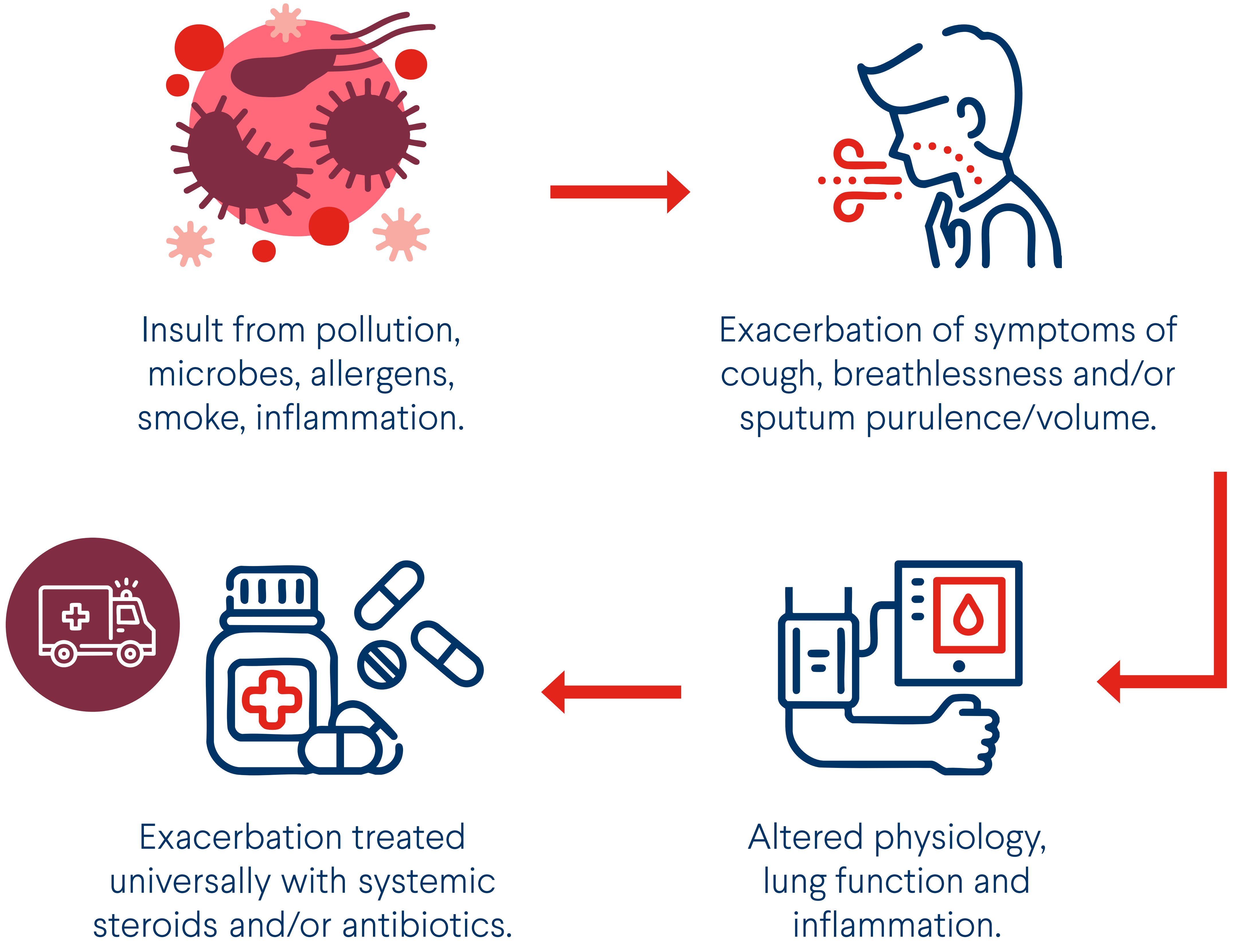
Air gets trapped in the lungs

Bronchial tubes become inflamed and narrowed

Thick mucus forms causing a chronic cough

When COPD flares up

COPD can lead to exacerbations – periods of acute worsening which can result in hospital admission, decline and death.



Insult from pollution, microbes, allergens, smoke, inflammation.

Exacerbation of symptoms of cough, breathlessness and/or sputum purulence/volume.

Altered physiology, lung function and inflammation.

Exacerbation treated universally with systemic steroids and/or antibiotics.

COPD exacerbation in the UK

Every 20 seconds

1 exacerbation every 20 seconds[4]

1 in 2

patients are readmitted or die within 90 days of exacerbation[5]

50%

chance of adverse events with treatment[6], and yet patients receive 'one-size-fits-all' management

4 x

more likely to have a myocardial infarction within 30 days of exacerbation[7]

50%

chance of surviving 2 years after a severe[8] exacerbation (worse outcome than some cancers)

COPD burden on UK services and society

1.4 million
people diagnosed[9]

›1 million
people undiagnosed[9]

30,000
deaths annually[9]

20 mins
1 death every 20 minutes[9]

3 mins
1 person hospitalised every 3 minutes[10]

£2 billion
annual NHS spend[2]

2nd
most common cause of emergency admissions[11]

1 in 8
acute adult medical admissions[12]

1.4 million
consultations in primary care annually[13]

67 years
average age at diagnosis[14]

11.2% vs 8.6%
men vs women affected[15]

5 x
more likely to get a lung cancer diagnosis[16]

1.8 x in women **1.4 x in men**
increased risk of mortality from cardiovascular disease[17]

Worldwide

384 million
people[18]

1 in 8
adults[18]

3rd
leading cause of death[19]

COPD
VOICES

Insights from lived experience of PwCOPD and recommendations for care

COPD VOICES

What did PwCOPD tell us?

Without treatment, the symptoms of COPD usually get progressively worse. There may also be periods when they suddenly get worse, known as a flare-ups or exacerbation.

Gasping
Fear
Short of breath
Smothering
Choking
Suffocating
Breathless
Exhausted
Drowning
Abandoned

‘I once heard someone say it took them an hour and a half to get up and dressed in a morning. I thought that was an exaggeration and not possible, but that’s me now! I have to rest after each little task due to the breathlessness.’

‘The fatigue is overwhelming.’

‘I am so scared of having a breathlessness attack. I thought I was dying on the last one. To be honest I wish I had died because I live in fear of another.’

‘The breathlessness attack was horrific. I wanted to die, I just wanted it to end and be over with. I peed myself it was so bad and I live in fear of it happening again. I’m widowed and on my own; it’s awful living with the likelihood of this happening again.’

COPD VOICES

‘I feel invisible to the NHS’

Raj (55) feels let down by her COPD management over the last 20 years and wonders if she would be in a better place if had she received earlier specialist support.

Previously a yoga teacher who enjoyed mountain climbing and marathons, Raj has seen herself ‘crumbling’ into someone with many limitations. She avoids going out because she struggles to walk and is embarrassed by breathing so noisily. Always ‘hungry for air’, she is unable to sleep at night and her throat is strained due to constant breathlessness.

Her GP, who she originally saw about increasing breathlessness, manages her COPD – she has never been to hospital. She was given an inhaler but no diagnosis. Some months later, when she applied for health insurance, the insurer requested to contact her GP for medical history. She was horrified to be told her application was dishonest for failing to declare her COPD – a diagnosis she was unaware of.

From the outset she has felt invisible to NHS systems. There’s been no information about her condition, no signposting for self-care, no annual check-up and no lung monitoring. She received a letter during the COVID pandemic telling her to shield but nothing else.

Her condition exacerbated two years ago when she had COVID and she was referred to a long-COVID clinic. They changed her inhaler but she didn’t get any information about self-management or the stage of her COPD.

Despite having stopped smoking, she took it back up in the face of mounting stress which was compounded by caring responsibilities for her partner and mother-in-law. They both have long-term conditions so she doesn’t feel able to talk to them about her own health problems. However, she is a champion for lived experience pathways for her local NHS trust, a member of a local people’s council, carers’ trust and carers’ advisory board and an advocate for Rethink Mental Illness.

> ‘The system forgets people like me – it’s a matter of life and breath.’

Raj’s wish list:

- More information at diagnosis with a clear pathway that highlights next steps in the COPD journey.
- Regular monitoring of lung health status, including a lung check at least annually.
- An FAQ resource compiled by people with with lived experience of COPD.
- Access to pulmonary rehabilitation or Sing to Breathe classes.
- An end to the postcode lottery of COPD care she and others experience.

COPD VOICES

‘You just don’t know what to do’

Celia (81) says the lack of information about COPD prevents people from taking care of their own health.

Despite having lung issues for almost 20 years, it took Celia two years to get her GP to acknowledge there was a problem.

She asked about doing pulmonary rehabilitation but was questioned on why it was necessary. When her symptoms progressed four years later, she had a chest X-ray and a consultant diagnosed her with emphysema. It was only then that she was offered pulmonary rehabilitation.

After having COVID things started to deteriorate, with more laboured breathing and reduced oxygen saturation. She also had to start insulin for type 2 diabetes.

Around this time she realised she was the only person at her Breathe Easy* group who wasn’t seeing a respiratory consultant, so she asked for a hospital referral and finally got a diagnosis of COPD. This was several years in the making.

A pattern of flare ups followed, each needing hospital admission but there was no post-discharge follow-up and she was back in hospital within three months. After a total of eight admissions she felt the flare ups were not well managed because her overall health deteriorated with each hospital stay.

She decided to transfer her treatment to another hospital and since then she’s seen a significant difference in her health. They found her oxygen levels were dangerously low and started oxygen therapy. After a year of using a BiPAP (bilevel positive airway pressure) machine, otherwise called non-invasive ventilation (NIV), at night and ambulatory oxygen when she goes out, she’s had no flare-ups, and has been able to switch to oral diabetes medication.

Nevertheless, everything feels like a struggle but she gets huge support from the local Breathe Easy weekly sessions which are her lifeline. She gets great care too from her current hospital and her GP practice now has a very knowledgeable nurse, who is supportive but she feels the lack of annual face-to-face monitoring with spirometry is detrimental to PwCOPD.

*Affiliated to Asthma + Lung UK

Celia’s wish list:

- Information about living well with COPD and how to access financial benefits as well as social support.
- Annual face-to-face monitoring with spirometry.
- Better access to GPs, pulmonary rehabilitation, Breathe Easy and other peer support groups.

COPD VOICES

‘I’ve decreased my lung age gap by over a decade!’

Anita (59) who at 52 had the lungs of an octogenarian says PwCOPD shouldn’t underestimate the power of breathwork.

Anita was diagnosed with COPD in her late forties not long after retiring from running her own business.

Previously a social smoker, she stopped smoking some 10 years ago, exercised regularly and attended boot camps three times a week for fitness.

When the symptoms first started she was experiencing some particularly stressful life events and didn’t take much notice. However, the breathlessness got worse when she exercised, so when life settled down she saw her GP and was referred to a respiratory consultant.

As her lung function declined she was given a COPD diagnosis and Ventolin inhaler. After a few years she started exploring how she could help her condition and found out about pulmonary rehabilitation. This was when she discovered ‘breathwork’ and began practising specialised yoga breathing techniques known as pranayama. She saw significant improvements in her lung function, energy levels, overall health and particularly her mental health. She also lost the four stone in weight she had gained by not having the breathing capacity to exercise.

At her annual lung health checkup, the improvements were so large the shocked respiratory nurse thought the spirometry equipment might be faulty and referred her to a doctor in case there had been a misdiagnosis!

She feels this remarkable change is a result of practising the breathing techniques, something that can be done as part of a self-management programme.

At this time, she no longer needs inhalers regularly and manages her lung health by anticipating what she terms ‘bad air days’ – when conditions are particularly hot, cold, humid or polluted – and taking steps to minimise the effects.

Now a qualified yoga teacher she teaches breathwork to other people with respiratory conditions like COPD. She runs sessions and workshops at local Breathe Easy groups and a gym which she would like to expand further. Recently she appeared on a BBC programme talking about the value of these techniques in COPD*.

*BBC Morning Live 17 Jan 2025 @ 44 mins

Anita’s wish list:

- Universal access to pulmonary rehabilitation from diagnosis.
- Greater awareness of self-management programmes for people with lung conditions and support for at-home teaching.
- Passionate non-judgmental professionals who understand respiratory conditions.
- Education for all community staff on the problems conditions like COPD bring.
- Awareness that smoking is not responsible for all lung disease – children who have asthma don’t smoke.

COPD VOICES

Giving a voice to PwCOPD

We wanted to give people with lived experience of COPD the opportunity to **share their stories** to get an insight into the challenges they face, both locally and nationally.

As with any healthcare challenge, understanding and articulating the problems and challenges faced by those living with a condition, and their carers, is always the first step towards solutions to improve care.

We know through our network of clinicians, that certain groups are more impacted by COPD. To give under-represented groups the chance to be heard we sought as many different voices as possible from a wide range of backgrounds.

The consultation period ran for eight weeks between September and November 2024 in seven different regional areas. To ensure accessible ways for participants to contribute their thoughts in a way that felt most comfortable we offered a choice of group workshops (either face-to-face or virtual) and individual interviews which ran for 60–90 minutes.

A range of views and experiences of health and care were collated from a total of 120 PwCOPD and their families and carers (including bereaved carers) who took part in the workshops and interviews.

What is going well with your care?

What aspects of services could be improved or need to change?

What are the challenges of living with COPD?

How long did you have symptoms before referral and diagnosis?

About the participants:

59%	female
41%	male
6%	under age 55 years
21%	age 55–65 years
73%	age 65+ years

COPD VOICES


Taunton workshop

Southampton workshop


We need change: Key recommendations

PwCOPD feel abandoned in three key areas: at the diagnosis stage, managing their condition and accessing support. All of these aspects of care are needed for a **better quality of life**.

From the workshops and interviews we were able to build a detailed picture of what it feels like to live with COPD. In addition to these three themes, the experiences of PwCOPD and their carers highlights an overarching problem of **inequitable COPD services that vary significantly by location**.

The rest of this report explores these themes utilising insights from PwCOPD to understand how services are currently being delivered and a set of recommendations for meaningful improvement. An integrated care pathway approach to COPD management will need to be adopted to realise all nine recommendations.

Recommendations from lived experience:

Diagnosis

- Prompt and accurate diagnosis.
- Provide comprehensive information about COPD.
- A national standard of COPD education for healthcare professionals.

Management

- An integrated COPD care pathway that equips multidisciplinary healthcare professionals to manage PwCOPD at all stages.
- Ensure annual review and timely ad hoc review when exacerbation is suspected.
- Educate healthcare professionals and PwCOPD on current and emerging therapeutic options.

Access

- A regional network approach to multidisciplinary team management with care closer to home with appropriate use of primary, community and secondary care.
- Equitable access to manage all aspects of a PwCOPD's needs (e.g. pulmonary rehabilitation, psychological support, and research activity).
- Tailored support for seldom-heard groups.

COPD VOICES

Diagnosis

Accurate diagnosis is essential to improving outcomes for COPD. Several people said they had symptoms such as breathlessness and persistent cough for many years and were told they had emphysema or bronchitis but not that it was or had progressed to COPD.

Where PwCOPD were managed in primary care, healthcare professionals were very often “too busy” and no one was available to spend time discussing their diagnosis with them. Some reported receiving their diagnosis via the NHS App or in a letter and very few were given a management plan, or directions on how or where to access one.

Access to information at the time of diagnosis empowers PwCOPD to make informed decisions about their health, treatment and overall wellbeing. It plays a key role in improving their ability to cope with the challenges of the disease and enhances their quality of life. However, most people received no information or very little information either at diagnosis or in the form of written information to take home.

Where written information was provided, it was difficult to understand due to complex terminology and abbreviations, or because English was not their first language. Only a small proportion of people were given sources of reliable information and support which left some unsure of what to do next.

Although the National Institute for Health and Care Excellence (NICE) recommends five fundamentals (5Fs) of care for PwCOPD[20], there remained an alarmingly high number who are missing out on the basic standards of high-value care creating a huge burden for health services as well as patient distress.

> ‘The nurse and consultant now are really good but it’s been years since I was diagnosed – in the time between then and now there was no information.’

> ‘It feels like I’ve been written off now I have a diagnosis of COPD. They may as well have said ‘this is terminal, there is no hope’, but I’m not at the stage to give up yet.’

COPD VOICES

Diagnosis

PwCOPD highlight critical delays in accurate diagnosis

- Many report not being diagnosed for years which impacts treatment effectiveness but also leaves PwCOPD feeling frustrated and unsupported.
- Some had symptoms of breathlessness and persistent cough for some time before they were diagnosed which was attributed to 'smokers cough', by themselves or healthcare providers.
- PwCOPD felt that despite multiple visits, GPs often trivialised symptoms and did not investigate further, or referral for specialist opinion was delayed.
- Several people only discovered their confirmed diagnosis on the NHS App or in a hospital letter.

> 'My COPD was only discovered when I went for surgery – I had been seeing the doctor with multiple chest infections and a persistent cough, but they did not even listen to my chest.'

Recommendation:

Prompt and accurate diagnosis

How could this recommendation be implemented?

- Always be thinking: could this be COPD? Early and accurate diagnosis enables PwCOPD to benefit from prompt treatment.
- Undertake spirometry as early as possible, particularly for smokers with symptoms of breathlessness and cough or recurrent chest infections.
- Access to digital technology like intuitive stethoscopes and remote spirometry could support earlier diagnosis.

COPD VOICES

Diagnosis

PwCOPD need better information at diagnosis

- The majority of PwCOPD received no or very little information at diagnosis, with no opportunity for discussion and were unaware of where to go for this.
- More support and guidance is needed to aid understanding about how to effectively self-manage COPD and maintain quality of life.
- People want COPD-specific resources about their condition and its management, such as What is COPD? and a COPD patient passport, to help to make informed decisions about their health and treatment.

> ‘There is no consistency of information and no coordination. Healthcare professionals all tell you different things – it needs coordinating.’

> ‘The information provided varies greatly. There is no consistency: one person says do this, another cautions against it. It seems the professionals don’t even talk to each other about how best to manage us!’

> ‘The initial diagnosis and lack of information was a shock. I googled it, I didn’t know where else to go. I felt cast out, he said ‘it’s COPD, now go and live with it’….’

> ‘It would be helpful for someone to sit down with you and explain it all instead of using Dr Google. I have to fight for everything I get.’

Recommendation:

Provide comprehensive information about COPD

How could this recommendation be implemented?

- Provide PwCOPD information at the time diagnosis about living with COPD in accessible formats.
- More knowledge of COPD is needed by community and primary care healthcare professionals so that discussions on COPD management can take place closer to home.
- Be more explicit on sources of information for PwCOPD.

COPD VOICES

Diagnosis

A lack of management plans to support PwCOPD from diagnosis

- Despite the majority of PwCOPD being managed in the community, PwCOPD say they are not getting a comprehensive management plan at diagnosis.
- Many people do not feel confident about managing their own condition once they have a diagnosis of COPD or how to respond to early warning signs of problems.
- Community multidisciplinary healthcare professionals need more education to understand COPD with a focus on the four fundamental pillars of COPD care as well as prevention, lifestyle interventions and wellness.
- Written management plans could incorporate patient-initiated follow-ups (PIFU), screening for and managing comorbidities and other social determinants of health, as well as access to digital technologies such as remote self-monitoring.

> ‘I always used both inhalers one after the other; I didn’t realise it was wrong.’

> ‘As soon as you say I have a cough the response is it doesn’t warrant a GP contact. I try to explain I have COPD but it’s a standard end of conversation.’

> ‘After diagnosis there was nothing. No contact from my GP who doesn’t seem to appreciate what’s happening. GPs are not designed to manage COPD.’

Who are participants managed by?

57%
by their GP

43%
by specialist teams in secondary care

Recommendation:

A national standard of COPD education for healthcare professionals

How could this recommendation be implemented?

- Ensure GPs, community and primary care staff are educated on diagnosis and management that incorporates the 5Fs of COPD care[20] from the outset:

  1. Self-management plan
  2. Support to stop smoking
  3. Pulmonary rehabilitation
  4. Flu and pneumococcal vaccinations
  5. Discussion of co-morbidities.

- Explain what will happen after diagnosis and provide a written management plan.
- Provide educational materials, resources and a COPD patient passport at diagnosis to better inform PwCOPD about their condition and management.

Management

There is enormous variation in care following diagnosis. PwCOPD frequently wait a long time for follow-up and discussions about treatment, management and monitoring of their condition. Many said they would like regular lung function tests to monitor their progress. **Use of digital technology for home monitoring was acceptable to those who had access to online resources.**

It is very difficult to get face-to-face appointments with GPs but where PwCOPD do have access to specialist nurses or healthcare professionals with specific expertise in COPD they find it extremely beneficial. It is often unclear how PwCOPD should make contact with healthcare professionals when they need specialist advice and clear information on how to access services is needed.

Many people are happy to have some services delivered remotely by phone or video call following their diagnosis. Telephone appointments were helpful. Video calls in a peer-group format, managing different aspects of COPD, were also deemed very useful. Both these remote services enabled PwCOPD, including 'getting to know others with COPD' locally. Cultural sensitivity, ethnic diversity and translation services with culturally-appropriate information, is essential.

Integration in the way services are currently delivered appears to be limited, with variable communication between specialist services and the community. PwCOPD require ongoing support, yet this is hampered by gaps in joined-up care. There are universal concerns that NHS systems do not speak to each other.

Better communication between respiratory services and community care is needed as GPs and community healthcare professionals play a major role in the everyday management of COPD symptoms, treatment and coordination of care.

'Surviving' was a recurring word. PwCOPD struggle to get access to timely GP care, obtain prescriptions and navigate the healthcare system. This led to frustration and feelings of being a 'second class' citizen.

PwCOPD tell us that healthcare professionals can be dismissive of them. Better education of healthcare professionals, aligned to the distinct challenges associated with severity and treatment are needed. The issue of participation in research opportunities was also voiced as the majority of PwCOPD attending the focus groups had not been offered opportunities to participate.

> 'It's exasperating when you call your GP and you are caller number 86! I can't do this anymore. I have to get my daughter to ring.'

> 'I couldn't get hold of my GP so I dialled 111 and they just sent an ambulance to take me to hospital. This has happened to me twice.'

COPD VOICES

Management

PwCOPD report poor coordination between healthcare providers and inadequate follow-up

- Marked variation exists in the quality and availability of COPD management between different areas and healthcare providers.
- There is a concerning lack of follow-up for those managed in primary care.
- PwCOPD find healthcare professional discontinuity makes it difficult to build trust and effectively manage their condition.
- An integrated care pathway is needed to ensure joined-up hospital and community care, improve health equity and reduce inequalities.

> ‘COPD has made me lose my dignity. I am no longer in control and I hate the feeling of helplessness, it’s so depressing.’

> ‘My COPD is harder to manage than my cancer. It’s very clear what I need to do for my cancer care and there is good information. The oncology team are great but I’m in a wilderness with COPD.’

> ‘I feel like I’m fighting this alone; no one understands how hard it is.’

> ‘Until you are in the ‘system’ you don’t get anything or anywhere’, ‘but how do I get in the system? COPD doesn’t seem to be a priority condition.’

About the participants:

73%
age 65+ years

27%
widowed

Recommendation:

An integrated COPD care pathway that equips multidisciplinary healthcare professionals to manage PwCOPD at all stages

How could this recommendation be implemented?

- A comprehensive integrated COPD care pathway to equip all healthcare professionals to manage patients and optimise treatment at all stages of the disease. This should provide joined-up services and improved health equity.
- All Integrated Care Boards (ICBs) should have respiratory champions from primary and secondary care.
- Access to digital solutions for self-monitoring lung function in between follow-up appointments.
- Provide a COPD patient passport to inform and monitor PwCOPD.

COPD VOICES

Management

Difficulty getting regular lung health checkups and interventions for flare-ups

- Unavailability of GP appointments is a major issue especially at the onset of a possible flare up. Timely intervention can avoid emergency hospital admission.
- Regular lung health checks have largely stopped. PwCOPD worry their disease progression is not being monitored and suggest remote monitoring via video link, telephone or monitoring devices might be suitable for those that have access.
- PwCOPD appeal for better support in managing exacerbations, including access to medication or a system like virtual wards where PwCOPD can safely manage minor flare-ups at home.

> ‘I ring for a GP appointment I may as well forget it; they give me one in two weeks – if I’m bad I go to A&E at least I get seen there.’

> ‘The receptionist says you can’t have a rescue pack refilled until the GP sees you but there are no appointments available. When you ring up you are in a queue and by the time you get through all the appointments have gone so its start all over again tomorrow.’

> ‘(Drug) trials are marvellous! I’ve been very well since I started treatment with no exacerbations and a reduction in mucous, which helped significantly with my breathing.’

Recommendation:

Ensure annual review and timely ad hoc review when exacerbation is suspected

How could this recommendation be implemented?

- Ensure PwCOPD are reviewed annually against the fundamental pillars of COPD care.
- Timely intervention should be available to PwCOPD if they suspect a flare up.
- There should be respiratory champions in each ICB in the community and secondary care.
- Digital solutions like apps and video calls are useful for some PwCOPD.

Participant experiences in 2024:

61%
saw their GP about COPD-related problems

65%
experienced a flare up

41%
admitted to hospital

16%
admitted to hospital more than once

COPD VOICES

Management

Gaps in patient and healthcare professional understanding of therapeutic options for COPD

- Ensure GPs, primary care and community teams are aware of all therapeutic options for COPD including **biologics, lung volume reduction surgery including endobronchial valves and lung transplant.**
- PwCOPD need comprehensive education to ensure they understand their treatments and how to use them effectively.
- PwCOPD express concerns about the effectiveness of their medications, particularly when switched to cheaper alternatives, while many struggle with proper inhaler technique due to inadequate guidance.
- As new treatments emerge, such as biologic therapies, PwCOPD express a strong interest in information and access to these options, including opportunities to participate in research.

> ‘If biologic drugs are okay for us from the research trials, they still need to get approvals from NICE, and if we get that will the government actually make money available for these treatments?’

> ‘The biologics had a really positive impact on my health and wellbeing, but will they be available to everyone?’

> ‘If I’m not well I may have used my inhaler a bit more, but if I ask for another I am told I’ve had my quota for the month. They don’t seem to realise that if I’ve used it extra times I will need a prescription earlier.’

> ‘I would be willing to take part in trials but it has never been spoken about.’

Recommendation:

Educate healthcare professionals and PwCOPD on current and emerging therapeutic options

How could this recommendation be implemented?

- Educate healthcare professionals and PwCOPD on current therapeutic options including availability of biologic treatments.
- This education can be through the development of a patient pathway.

About the participants:

57%

of participants are managed solely by their GP

Access

Transformation of respiratory services will involve COPD care delivered through a tiered multidisciplinary approach. This means it is vital that services to support PwCOPD are accessible closer to home.

Peer support can be invaluable for PwCOPD. But in those where English is not the first language, there is a lack of this type of support. These need to be inclusive to reduce health inequity.

The lack of COPD-specific services means many PwCOPD have no knowledge of sources of support and information. There was a plea for earlier access to support groups.

Pulmonary rehabilitation is an important tool in improving the quality of life for PwCOPD as it provides a comprehensive and tailored approach to improving lung function.

PwCOPD are very positive about the benefits of pulmonary rehabilitation, but feel it is not offered early enough or is not accessible, particularly for those for whom English is not a first language. Many reported difficulty accessing pulmonary rehabilitation, with very long waits or the amount offered limited.

In some areas, pulmonary rehabilitation is only accessible once annually, whereas other areas have no availability at all.

> ‘We had no help for 15 or 16 years and then we were referred to pulmonary rehab. It was a turnaround for us. We thought it was a condition you just had to put up with.’

> ‘I’m petrified that we are going to lose some of these things (park walks and singing), they have made such a difference to my breathing.’

> ‘There are lots of others that have this awful disease but we need to find them – others can give information about how to manage problems. A self-help group would be wonderful.’

Access

Service change is critical to level up health disparities

- Where PwCOPD do have access to specialist nurses or healthcare professionals with specific expertise in COPD they find it extremely beneficial, but not everyone with COPD has this opportunity.
- Access to specialist diagnosis and care is currently inequitable. All PwCOPD should have as much access to best practice care; delivered locally as is feasible and safe; as well as equitable access to commissioned treatments.
- Integrated tertiary, secondary and community care for COPD needs to be coordinated into ICB networks which would enable:
  - Access to community/primary care with necessary skills in COPD management.
  - Commissioning of sufficient vital local care including pulmonary rehabilitation and psychological support.
  - Access to multidisciplinary team advice and decision support closer to home.
  - Access to research opportunities.

> ‘I feel like a second-class citizen – I’ve never smoked but everyone assumes I have. I’ve always worked in industry and I think that has contributed to my chest problems.’

> ‘The respiratory nurses are just brilliant, they get back to you straight away.’

Recommendation:

A network approach to multidisciplinary team management with care closer to home with appropriate use of primary, community and secondary care

How could this recommendation be implemented?

- A networked approach to COPD management and multidisciplinary team decisions which enables local administration of all treatments including biologics closer to home.
- Access to research opportunities particularly for non-smokers and those living in industrialised areas.

COPD VOICES

Access

Vital services for support such as pulmonary rehabilitation are limited or involve very long waits

- While pulmonary rehabilitation is crucial for COPD management, many PwCOPD struggle to gain access.
- Sing to Breathe, Breathe Easy and peer support groups are highly regarded but again access is variable depending on location and may not be accessible to non-English speakers.
- The psychological impact of COPD is often overlooked. PwCOPD report depression, anxiety, isolation and a lack of mental health support for COPD. Virtual Talking Therapies Hampshire was noted as a helpful and accessible online form of support.
- PwCOPD recognise the importance of exercise, diet and breathing exercises to improve exercise tolerance, mood and quality of life; however, people struggle to access appropriate facilities and report that insufficient support is available.
- The NHS could partner with local authorities to provide affordable, accessible exercise options tailored to PwCOPD, such as health walks, supervised swimming sessions or specialised fitness classes.

> ‘I feel we are given a label of COPD and thrown away because there is nothing that can be done. There is stigma around the condition everyone assumes you are a smoker and I was, but I also lived in an industrialised area with smoke from factories. I worked in the steel works from being 16 breathing in fumes. My mum was a single parent we had a poor diet. I think these things contributed.’

> ‘I could be sat at home and breathless and not know what to do. I have no understanding of what to expect. How can I look for things to support me when I don’t know what to look for? I’ve heard about stuff like pulmonary rehab in this discussion that I’ve never heard of before.’

> ‘I am grieving the life I had. My body won’t let me do things so I have to do something. Smoking gives me something to do with my hands.’

Recommendation:

Equitable access to manage all aspects of the needs of PwCOPD (e.g. pulmonary rehabilitation and psychological support)

How could this recommendation be implemented?

- Ensure that the majority of PwCOPD have access to core services: pulmonary rehabilitation, oxygen assessment and psychological therapies including peer group support.

About the participants:

67%
of participants said their condition limits daily activities

37%
of those have mobility issues

COPD VOICES

Access

Addressing health inequalities

- There are marked variations in post-diagnosis care based on a person's location. Participants highlighted differences in the quality and availability of the COPD services they needed depending on where they live and the healthcare providers they access. This is compounded by health inequalities such as deprivation, rurality and ethnicity.
- Chronic lung diseases like COPD have stark health inequalities with dramatically different morbidity and mortality.
- The NHS needs to address these access barriers urgently, ensuring that all PwCOPD get the support they need and can receive timely and appropriate care, whether through in-person or virtual consultations.

> 'I can only order my prescriptions on an app which I can't use. I have to go to the surgery to speak to them every time and they see me as a nuisance and keep saying 'do it online' but I can't manage. I used to order by phone but they have stopped that now!'

> 'It's really difficult for my sister, she can't read or write and only speaks Gujarati. Thankfully her GP speaks it too, but other healthcare providers don't. We have to be there for every appointment.'

> 'Appointments are all on different days. I can't afford a taxi to get to them all and there's no bus service here.'

> 'Surely there are groups I could go to, but where are they? I don't have internet – how do I find out? Everything is online these days; what about people like me that can't afford a phone?'

> 'Not enough is done about telling us about benefits. I shouldn't have to fight for what I'm entitled to.'

Recommendation:

Tailored support for seldom-heard groups

How could this recommendation be implemented?

- Ensure tailored support for minority groups, those in rural and coastal locations or areas of deprivation.
- Nationally there should be a COPD health inequality toolkit, as part of the NHS Race and Health Observatory.

About the participants:

2%
African Caribbean

14%
Indian or Pakistani

3%
Homosexual

1%
Gypsy or Irish traveller

Deciles
1–10
of the Index of Multiple Deprivation were represented in each region

COPD VOICES

Giving carers a voice

The burden on friends and family is significant and many carers report struggling to cope with their responsibilities. Where available, carers describe support groups as very important and motivating.

Participants highlighted the personal costs of their caring role which impacts significantly on their own lives affecting relationships, work, finances and time for themselves.

Carers feel unsupported, undervalued and isolated in their roles. They provide a range of care including clinical tasks, medication provision and emotional support.

The majority of carers we spoke to were over 65 and coping with their own long-term conditions like diabetes and heart disease with reduced ability to focus on their own needs.

Younger carers also highlighted their role as a main carer was not the life journey they expected.

Only one person had been given their own carer's assessment and several were not aware of carer's benefits.

Financial issues were raised several times with the cost-of-living crisis having a profound impact on many. Heating, food and increased fuel expenses are constant concerns.

Financial difficulties add stress and anxiety for carers who are already facing challenges with their caring roles. Falling into debt or cutting back on activities that improve their own health and wellbeing were highlighted.

> 'There's no thought for carers – we were at breaking point not knowing what to do.'

> 'I'm feeling very low and drained mentally and physically. I can't let my mum see that so have to put on a happy face but I'm definitely struggling and worry about what will happen to her if I break.'

> 'I've spoken with my doctor and tried to find help online. The waiting list for counselling is off the scale and then only provides six hours when you get it. How can that help long term? Doctors want to prescribe anti-depressants but that's not what I need. They don't get it, I'm exhausted caring.'

> 'It's difficult to switch off, constantly thinking about his needs and solving issues as his condition worsens.'

Recommendation:

- **Give carers a voice and ensure they are involved and listened to.**
- **Carers' role in supporting PwCOPD is often undervalued. They need comprehensive support systems including respite care, training, and access to support groups.**

> 'Amid physical caring came the stark reality of navigating the healthcare system, which often felt daunting and inadequate. The lack of clear communication from healthcare professionals, particularly during the diagnosis of the COPD, left us grappling with uncertainties about the future.'

About the participants:

29%
were carers

3%
were carers age 18–25 years

50%
of carers undertake caring 50+ hours/week

Realising change

Using COPD voices to inform effective service transformation in the NHS

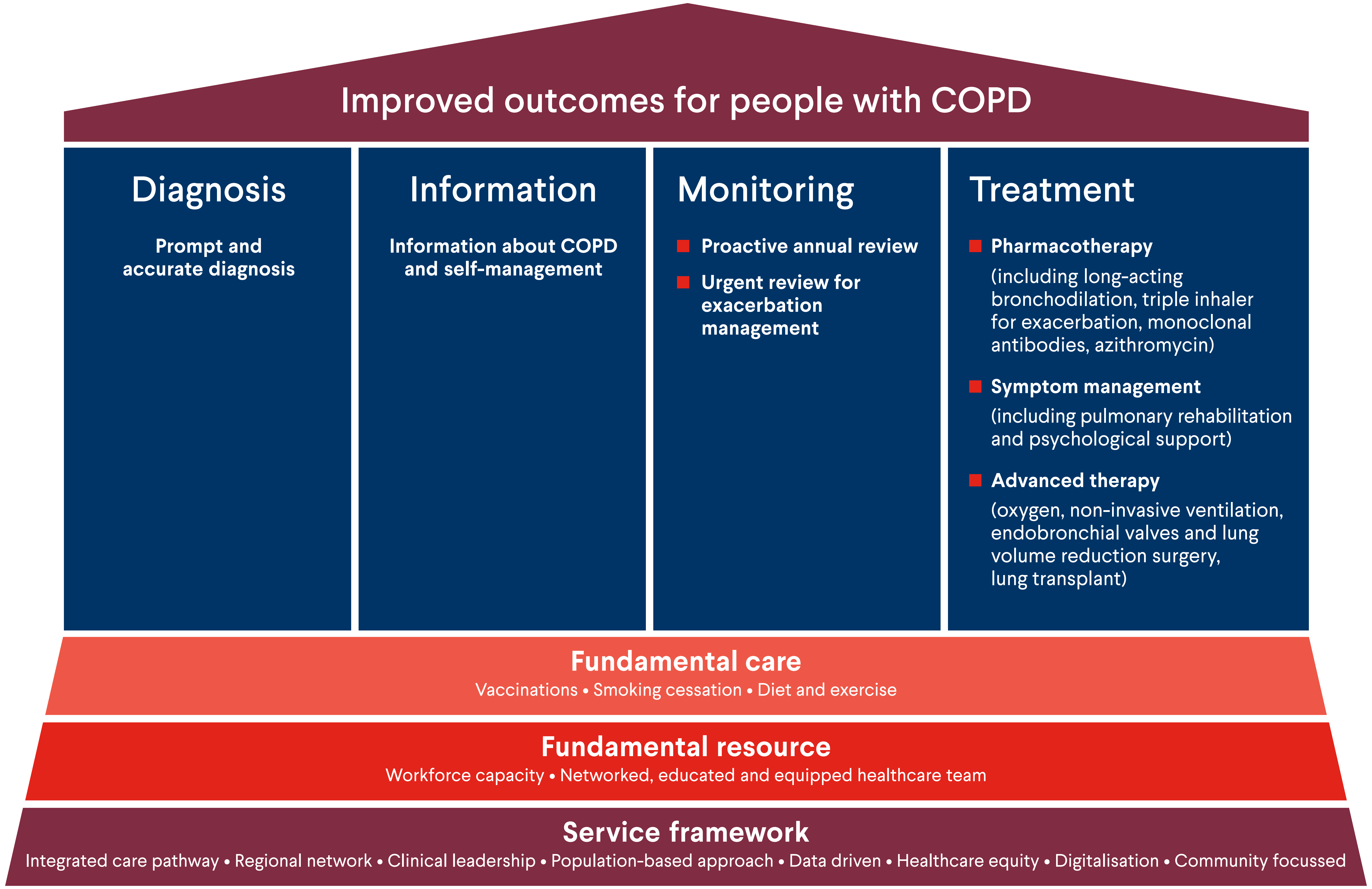
The fundamental pillars of COPD care

Providing systems with enablers to deliver optimal COPD care in line with delegation of services.

This report provides a powerful insight into lived experiences of COPD and produces key recommendations from people with the condition.

To help realise change and improve outcomes and quality of life for PwCOPD, clinicians have developed these recommendations into a comprehensive model for optimal COPD care, which consists of four fundamental pillars:

The pillars rest on a base of:



Improved outcomes for people with COPD

Diagnosis

Prompt and accurate diagnosis

Information

Information about COPD and self-management

Monitoring

- Proactive annual review
- Urgent review for exacerbation management

Treatment

- **Pharmacotherapy**
  (including long-acting bronchodilation, triple inhaler for exacerbation, monoclonal antibodies, azithromycin)
- **Symptom management**
  (including pulmonary rehabilitation and psychological support)
- **Advanced therapy**
  (oxygen, non-invasive ventilation, endobronchial valves and lung volume reduction surgery, lung transplant)

Fundamental care

Vaccinations • Smoking cessation • Diet and exercise

Fundamental resource

Workforce capacity • Networked, educated and equipped healthcare team

Service framework

Integrated care pathway • Regional network • Clinical leadership • Population-based approach • Data driven • Healthcare equity • Digitalisation • Community focussed

These structural components are explored in the following pages accompanied by a set of delivery enablers for service transformation. We highlight how these enablers align with the three strategic shifts for effective change in the NHS[3]:

Shift 1 → Moving care from hospitals to the community

Shift 2 → Embracing digital transformation

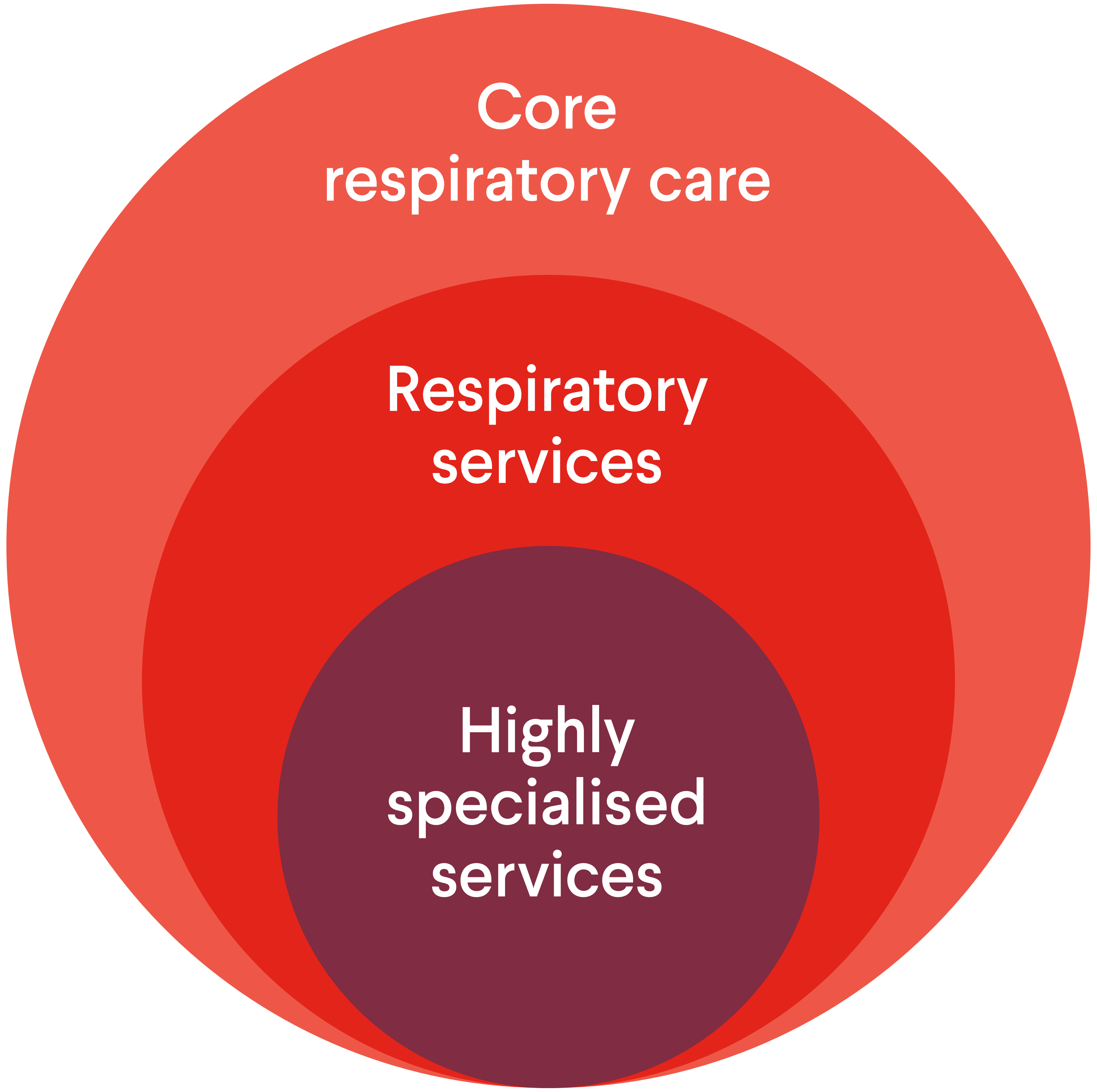
Shift 3 → Shifting from treatment to prevention

As the second most common cause of emergency admissions in the UK[11], it is essential that COPD has a place in Integrated Care Board (ICB) priority-setting discussions. Integrated Care Systems (ICSs) have an opportunity to deliver high-impact interventions, for example by offering community respiratory services, specialist care closer to home, improved acute respiratory pathways and support for PwCOPD to live well.

A networked delivery model

The fundamental pillars of COPD care could be delivered across a networked model for respiratory services.

This model emphasises type of care and de-emphasises location of delivery. All services should be equitably accessible from every ICS.



● **Core respiratory care**

Primary, community and secondary care services (inpatient/acute outpatient, out of hospital, remote monitoring, virtual consults) commissioned by ICBs and planned at ICS level (e.g. spirometry, pulmonary rehabilitation, oxygen, biologics).

● **Respiratory services**

Services providing diagnostic treatment and support to PwCOPD with complex needs who cannot be managed by a core respiratory service alone (primary, community, secondary, inpatient/acute outpatient, out of hospital). These services need to be planned at ICS or multi-ICS level. National standards and specifications apply and NHS England is accountable for delivery, e.g. non-invasive ventilation (NIV), cardiopulmonary exercise testing (CPET).

● **Highly specialised services**

Nationally defined specialist services delivered in a small number of centres. Directly managed by highly specialised services and commissioned by NHS England, e.g. lung transplant and lung volume reduction surgery/valves.

COPD service framework

Delegation of funding to Integrated Care Boards (ICBs) now provides an opportunity to join up currently fragmented commissioning pathways planned with PwCOPD. This allows coordinated services to achieve the best outcomes, managing local need, not just demand.

ICBs can transform and integrate management of COPD and with system-level planning enable local decision making to improve integration, enable greater flexibility to tailor services, and hold them accountable for care.

All this will be achieved through an integrated COPD care pathway and an ICB clinical network approach.

Integrated care pathway

Integrated care pathways are a multidisciplinary and multi-agency approach to outlining patient care from initial diagnosis across the whole course of the condition.

ICB clinical network approach

ICBs need to take a networked approach to the commissioning of respiratory services in order to deliver equitable access to integrated care for all respiratory conditions.

The 'three shifts' in NHS healthcare promote a community-focused approach where respiratory networks can deliver care safely and closer to home through a governance framework[3]:

- Setting standings and metrics
- Establishing appropriate funding mechanisms
- Sharing models and best practice.

NHS 'three shifts'[3]

Delivery enablers	Hospital to community	Analogue to digital	Sickness to prevention
Develop a local ICB integrated care pathway rooted in the fundamental pillars of COPD care with a whole patient, whole pathway focus	●	●	●
Use predication models to forecast prescribing needs/workforce needs	○	●	○
Understand how innovation can support pathway implementation	○	●	○
Involve PwCOPD and carers in development of a COPD local care pathway	○	○	●
Establish a regional network shared-care approach in delivering high quality care outcomes, improving system wide value and reducing health inequalities	●	○	○
Provide long term complex COPD management in the community to build capacity in specialist units	●	○	●
Greater liaison needed with ICBs for system-level planning	●	○	●
Develop respiratory champions in each ICB area linking community and secondary care	●	○	○
Make leadership development and training opportunities available for healthcare professionals, commissioners and service managers working across COPD care	●	●	●
Consider development of patient leaders to assist with improvement of COPD services at a network level and also provide influence from a number of angles with ICSs	●	○	●

Population-based management approach

The aim of population healthcare is to maximise value and equity by focusing not on institutions, specialties or technologies, but on populations defined by a common symptom, condition or characteristic.

It is essential that ICBs and specialist teams understand their own COPD population and how services are functioning so that good practice and unwarranted variation can be addressed.

Data-driven approach

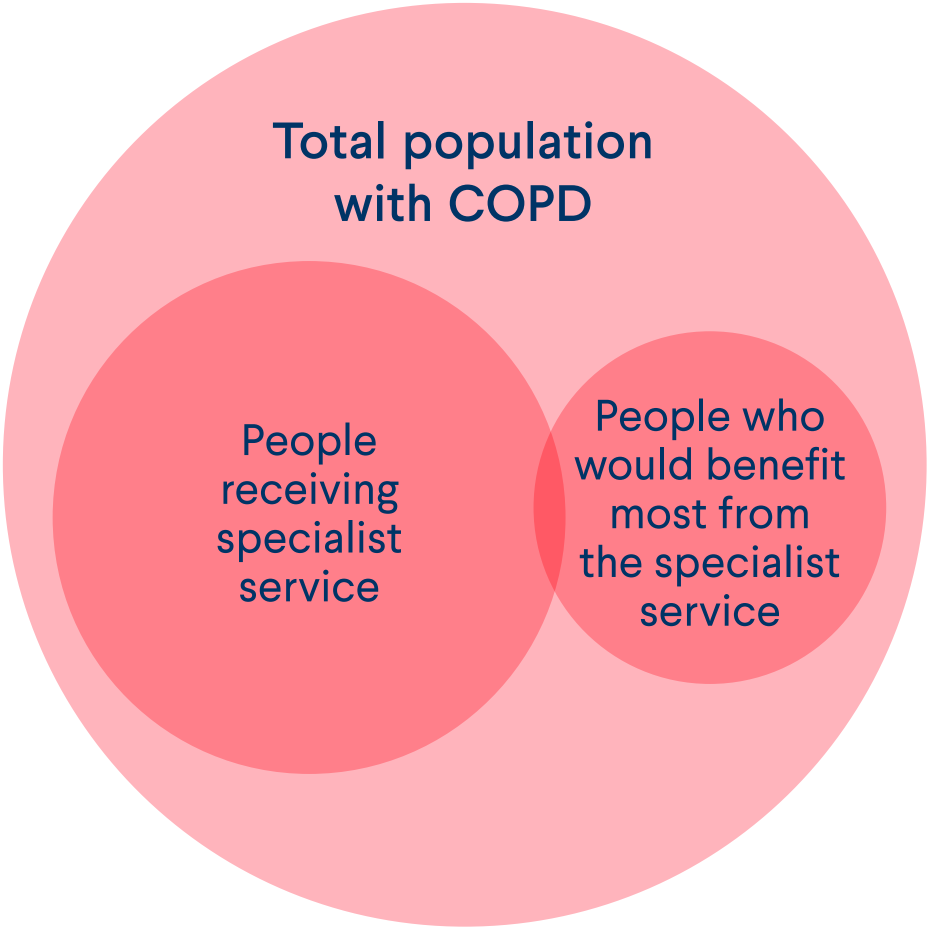
Use of data, backlog reporting, service audits, self-management and monitoring, and incentives all play a part in future service reform.

Digitalisation

Digital and remote-based solutions enable sharing skills across the system where there is specific skill/role shortages. Care needs to be taken to ensure equity as not all PwCOPD are digitally connected.

Healthcare equity

All respiratory services should be equitably accessible from every ICS, and fully accessible regardless of location, deprivation and language.



Enabling population health management for COPD: the importance of identifying people who would benefit most from the specialist service

Delivery enablers

NHS 'three shifts'[3]

Delivery enablers	Hospital to community	Analogue to digital	Sickness to prevention
Use data to identify interventions based on population health needs	○	●	○
ICBs adopt a whole patient whole pathway approach based on their local population needs	●	●	●
Review unmet need across the pathway	●	●	●
Identify metrics to support improvement in outcomes	○	●	○
Access to Patient Identifiable Data (PID) from primary care to link with BlueTeq data	○	●	○
Automate data collection and retrieval	○	●	○
Shared data access/reporting to support patient identification at local practice and system levels	●	●	●
Access to biologic prescribing data on national database	●	●	●
Use predication models to forecast prescribing needs/workforce needs	○	●	○
Management plans developed with patients	●	○	●
Target approach at local level through understanding risk factors and vulnerable groups (deprived areas, rural and coastal communities and for those for whom English is not a first language)	●	○	●
Provide easy and accessible information through appropriate channels and language	●	●	●
Peer support by patients with similar protected characteristics	●	○	●
Easy access to prescribing information/data across pathway	○	●	○
Single patient record	○	●	○

COPD fundamental resource and care

Workforce capacity

Education on disease complexity, and understanding that early escalation to treatment is essential. This must be understood by all stakeholders involved in the care and management of COPD. Preventative care for exacerbations should be a particular focus of education and awareness for the NHS workforce. This will strengthen efforts to build links with the voluntary sector and other services that can support patients, particularly for self management.

Networked, educated and equipped healthcare team

Future ways of working will move from a hierarchy to a networked shared care approach for delivering care. This will require clinicians including specialists to become population focused as well as supporting colleagues in the community to manage COPD patients. Education and digital links will be paramount to supporting competency in non-specialists.

ICBs can assess their existing services and improve access to skills in community/primary care through mapping existing services. This will help understand their flows to consider which elements can be delivered more efficiently, more locally or by ensuring the workforce is sufficiently skilled in COPD management.

Foundational care

All PwCOPD should expect a standard of care outlined in NICE guidelines and quality standards regardless of where they live.

NHS ‘three shifts’[3]

Delivery enablers	Hospital to community	Analogue to digital	Sickness to prevention
Use predication models to forecast workforce needs	○	●	○
Address human resource and capacity challenges through better utilisation of the workforce. This could be through skill mix and wider engagement with healthcare practitioners to undertake new roles that are developing as a result of Direct Enhanced Service (DES) in the community	●	○	○
Training and education across workforce and with people receiving care, competencies and peer-to-peer learning	●	○	○
Access to COPD expertise including Advanced Nursing Practitioner (ANP) expertise	●	○	●
Additional advanced practitioners, i.e. pharmacists, physiotherapists and occupational therapists	●	○	●
Clinical and Quality Improvement respiratory champions at local and regional level	●	○	○
Identify Primary Care Network (PCN) pharmacists to flag people who may need inhaler technique support and medication review	●	○	○
Integration of respiratory champions across all settings	●	○	○
Reduce the number of patients experiencing acute exacerbations by prioritising preventative measures such as smoking cessation services and proactive monitoring initiatives like virtual wards	●	○	●
Implement the 5Fs of COPD care[20]	●	○	○

Diagnosis

Prompt and accurate diagnosis

Accurate diagnosis is essential for treatment selection. With the increasing availability of biologics for treatment, early diagnosis provides an opportunity to enhance prognosis.

Information

Information about COPD

Access to information at the time of diagnosis empowers PwCOPD to make informed decisions about their health, treatment, and overall well-being. It plays a key role in improving their ability to cope with the challenges of the disease and enhances their overall quality of life. However, most people received no information or very little information at diagnosis, either during the consultation or in the form of written information to take home.

Support for self-management

PwCOPD should be encouraged to manage their condition – with support from others to help to understand COPD and manage symptoms, medication and how to cope with flare-ups. A self-management plan is also helpful.

NHS 'three shifts'[3]

Delivery enablers	Hospital to community	Analogue to digital	Sickness to prevention
Use flags/risk assessment tools to identify patients for referal	●	●	○
Implement the NHS England breathlessness pathway[21]	●	●	●
Shared data access/reporting to support patient identification at local practice and system levels	○	●	○
Improve diagnostic rates by facilitating consistent and timely access to testing	●	○	○
Establish targeted Lung Health Check programmes to identify and test at-risk citizens	○	○	●
Ensure COPD training and diagnostic tools are equitably available to all GP practices	●	●	○
Consider community diagnostic centres involvement in rapid diagnostic testing especially in community settings and deprived areas	●	○	●
Provide easy and accessible information through appropriate channels and language	○	●	●
Access to advice and guidance including peer support and voluntary sector sources	●	●	●
Peer support by patients with similar protected characteristics	○	○	●
Enable effective self management - establishing standardised pathways for the development of self-management plans and exploring the role of digital tools in supporting this	○	●	●
Ensure a COPD passport is available for every person with COPD to enable clarity around the COPD pathway and opportunities that exist for effective self-management	●	○	●

Monitoring

Proactive annual review

Without regular review, a person's condition may deteriorate unnoticed and opportunities to optimise their treatment may be missed. It is essential PwCOPD get a lung health review at least annually including checking the 5Fs of COPD care[20].

Urgent review for exacerbation management

There should be timely review for suspected exacerbation.

Treatment

Pharmacotherapy

The advent of new treatments like biologics provides an opportunity to 'reset' and 'reform' COPD services through recognition of these new treatment options. PwCOPD need equitable access to commissioned treatments.

- Dual long-acting bronchodilation
- Triple inhaled therapy (inhaled steroids and dual bronchodilation) for those with exacerbations
- Biologics therapy
- Azithromycin prophylaxis.

Therapies for advanced COPD include:

- Oxygen
- Non-invasive ventilation
- Endobronchial valves and lung volume reduction surgery
- Lung transplant.

Non-pharmacological therapy

Pulmonary rehabilitation is an important tool in improving the quality of life for PwCOPD as it provides a comprehensive and tailored approach to improving lung function. Other non-pharmacological therapies that are essential to COPD management include:

- Symptom management
- Mental health support
- Social care including carer support
- Smoking cessation.

Delivery enablers

NHS 'three shifts'[3]

Delivery enablers	Hospital to community	Analogue to digital	Sickness to prevention
Ensure annual review with lung health checks including the 5Fs of COPD care[20]	●	●	●
Provide more virtual clinics to reduce travel burden and build service capacity via respiratory networks	●	●	●
Timely appointments for suspected exacerbation identification and prompt management	●	●	●
Reduce the number of patients experiencing acute exacerbations by prioritising proactive monitoring initiatives like virtual wards	●	●	●
Access to biologic prescribing data on national respiratory database	○	●	○
Provide rapid access to novel therapies for those with COPD	●	○	●
Increase the provision and uptake of pulmonary rehabilitation services by offering services in community settings and updating clinical pathways to include a direct referral into these services	●	●	●

Glossary of terms

COPD
Chronic obstructive pulmonary disease

ICB
Integrated Care Board

ICS
Integrated Care System

NICE
National Institute for Health and Care Excellence

NIHR
National Institute for Health and Care Research

PwCOPD
Person/people with chronic obstructive pulmonary disease

Resources

Asthma + Lung UK. About COPD

Asthma + Lung UK (2022) COPD in the UK: Delayed diagnosis and unequal care

Change NHS. The three shifts

Global Initiative for Chronic Obstructive Lung Disease (2025) Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease: 2024 report

Healthwatch Essex (2024) Community Asset Mapping: Chronic Obstructive Pulmonary Disease

Healthwatch Suffolk (2024) "Like drowning in air" Lived experience report - Chronic obstructive pulmonary disease (COPD) support in Suffolk

NHS (2019) The NHS Long Term Plan

NHS England (2023) Adult breathlessness pathway (pre-diagnosis): diagnostic pathway support tool

NHS England. Core20PLUS5 (adults) – an approach to reducing healthcare inequalities

NICE (2011) Chronic obstructive pulmonary disease in adults: Quality standard [QS10]

NICE (2018) Chronic obstructive pulmonary disease in over 16s: diagnosis and management. NICE guideline [NG115]

NICE (2024) Digital technologies to deliver pulmonary rehabilitation programmes for adults with COPD: early value assessment. Health technology evaluation HTE18

NICE (2024) Digital technologies to support self-management of COPD: early value assessment. Health technology evaluation HTE19

Office for Health Improvement & Disparities (2022) Official Statistics. Interactive Health Atlas of Lung conditions in England (INHALE): February 2022 update

Primary Care Respiratory Society. Challenging perceptions of COPD

References

1. Buist AS, McBurnie MA, Vollmer WM, Gillespie S, Burney P, Mannino DM, Menezes AM, Sullivan SD, Lee TA, Weiss KB, Jensen RL, Marks GB, Gulsvik A, Nizankowska-Mogilnicka E; BOLD Collaborative Research Group. International variation in the prevalence of COPD (the BOLD Study): a population-based prevalence study. Lancet. 2007 Sep 1;370(9589):741-50.
2. POSB65 Economic Burden of COPD in the United Kingdom (2021–2040) Estimated with the COPD Health Outcome Policy and Intervention (CHOPIN) Model de Nigris, E et al. Value in Health, Volume 25, Issue 1, S72-S73
3. Change NHS. The three shifts. https://change.nhs.uk/en-GB/projects/three-shifts
4. Asthma and Lung UK (2022). COPD in the UK: Delayed diagnosis and unequal care. Executive summary. https://www.asthmaandlung.org.uk/sites/default/files/2023-03/delayed-diagnosis-unequal-care-executive-summary.pdf
5. Echevarria C, Steer J, Heslop-Marshall K, Stenton SC. The PEARL score predicts 90-day readmission or death after hospitalisation for acute exacerbation of COPD. Thorax. 2017 Aug;72(8):686-693.
6. Leuppi JD, Schuetz P, Bingisser R, et al. Short-term vs conventional glucocorticoid therapy in acute exacerbations of chronic obstructive pulmonary disease: the REDUCE randomized clinical trial. JAMA. 2013; 309:2223-2231.
7. Rothnie KJ, Yan R, Smeeth L, Quint JK. Risk of myocardial infarction (MI) and death following MI in people with chronic obstructive pulmonary disease (COPD): a systematic review and meta-analysis. BMJ Open. 2015 Sep 11;5(9):e007824.
8. NICE Chronic obstructive pulmonary disease: What is the prognosis? https://cks.nice.org.uk/topics/chronic-obstructive-pulmonary-disease/background-information/prognosis/
9. Asthma and Lung UK (2022). COPD in the UK: Delayed diagnosis and unequal care. https://www.asthmaandlung.org.uk/conditions/copd-chronic-obstructive-pulmonary-disease/world-copd-day/delayed-diagnosis-unequal-care
10. Department of Health and Social Care (2024) Fingertips Public Health profiles: COPD in England. https://fingertips.phe.org.uk
11. Snell N, Strachan D, Hubbard R, Gibson J, Gruffydd-Jones K, Jarrold I (2016) Epidemiology of chronic obstructive pulmonary disease (COPD) in the UK: Findings from the British Lung Foundation's 'respiratory health of the nation' project. Thorax, 71(3).
12. NHS Digital Transformation Directorate. Digital playbooks key tools and information. Care pathway playbooks, Respiratory digital playbook: Digital service to manage high-risk chronic obstructive pulmonary disease (COPD) patients. https://transform.england.nhs.uk/key-tools-and-info/digital-playbooks/respiratory-digital-playbook/digital-service-to-manage-high-risk-chronic-obstructive-pulmonary-disease-copd-patients/
13. NICE (2024), COPD: How common is it? https://cks.nice.org.uk/topics/chronic-obstructive-pulmonarydisease/background-information/prevalence-incidence/
14. Devereux G. ABC of chronic obstructive pulmonary disease: definition, epidemiology, and risk factors. BMJ. 2006;332(7550):1142–1144.
15. Burney P, Patel J, Minelli C, et al BOLD Collaborative Research Group. Prevalence and Population-Attributable Risk for Chronic Airflow Obstruction in a Large Multinational Study. Am J Respir Crit Care Med. 2021 Jun 1;203(11):1353-1365.
16. Young RP, Hopkins RJ. Link between COPD and lung cancer. Respir. Med. 2010;104(5):758–759.
17. Hippisley-Cox J, Coupland CAC, Bafadhel M, Russell REK, Sheikh A, Brindle P, Channon KM. Development and validation of a new algorithm for improved cardiovascular risk prediction. Nat Med 30, 1440–1447 (2024).
18. Adeloye D, Song P, Zhu Y, Campbell H, Sheikh A, Rudan I; NIHR RESPIRE Global Respiratory Health Unit. Global, regional, and national prevalence of, and risk factors for, chronic obstructive pulmonary disease (COPD) in 2019: a systematic review and modelling analysis. Lancet Respir Med. 2022 May;10(5):447-458.
19. World Health Organization (2024) Chronic obstructive pulmonary disease (COPD) https://www.who.int/news-room/fact-sheets/detail/chronic-obstructive-pulmonary-disease-(copd)
20. National Institute for Health and Care Excellence (NICE) 2019. Chronic obstructive pulmonary disease in over 16s: diagnosis and management NICE guideline [NG115]. https://www.nice.org.uk/guidance/ng115/
21. NHS England (2023) Adult breathlessness pathway (pre-diagnosis): diagnostic pathway support tool. https://www.england.nhs.uk/long-read/adult-breathlessness-pathway-pre-diagnosis-diagnostic-pathway-support-tool/

Acknowledgements

Sincere thanks to everyone who contributed to the production of this report by supporting recruitment of those living with COPD.

- Focus group participants who kindly shared their lived experience of COPD.
- Local Breathe Easy groups and the Primary Care Respiratory Society for circulating details of the focus groups.
- Clinicians and specialist respiratory teams within each of the NHS Regions surveyed.
- Pulmonary rehabilitation services for their support in disseminating information and encouraging people with COPD to join.
- The COPD National Biologics Consortium.
- Principal investigators or teams who recruited local PwCOPD:
  - Dr Gussie Beech, Manchester
  - Dr Hannah Burke, Southampton
  - Dr Michael Crooks and Joanne Thompson, Hull
  - Dr Marie Fisk and Alan Jensen Cambridge
  - Dr Neil Greening and Joanna Bell, Leicester
  - Prof John Hurst and Dr Tanya Patrick, London
  - Dr Shamanthi Maya Jayasooriya, Sheffield
  - Prof Mona Bafadhel and Gladys Monde, London
  - Dr Richard Russell, Lymington
  - Dr Dinesh Shrikrishna, Taunton

Project supervisors

- Mona Bafadhel, Research Professor NIHR304263 is funded by the National Institute for Health and Care Research (NIHR) for this project. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.
- Richard Russell, Consultant Chest Physician, Clinical Reader in Respiratory Medicine, King's College London.

Patient voices interviews were undertaken by Sue Thomas.

Report authors: Sue Thomas and Sarah Mehta, Healthcare Consultants.

Graphic designer: Matt Whitehead

This project was supported by the King's Health Partners Centre for Translational Medicine. The views expressed are those of the author(s) and not necessarily those of King's Health Partners.

Appendices

NHS policy

NHS Long Term Plan priorities

NHS (2019) The Long Term Plan. https://www.longtermplan.nhs.uk/

Lung conditions including lung cancer are estimated to cost wider society around £11 billion each year.

- Over the next ten years we will be targeting investment in improved treatment and support for those with respiratory disease, with an ambition to transform our outcomes to equal, or better, our international counterparts.
- Incidence and mortality rates for those with respiratory disease are higher in disadvantaged groups and areas of social deprivation.
- We will increase the number of patients with COPD who are referred to pulmonary rehabilitation.
- The NHS will do more to detect and diagnose respiratory problems earlier.
- We will do more to support those with respiratory disease to receive and use the right medication.
- Patients identified with community acquired pneumonia in emergency departments will be supported to be cared for safely out of hospital by receiving nurse-led supported discharge services.
- Test and learn demonstrators will be used to establish an evidence base for joint cardiac and pulmonary rehabilitation models.

Core20PLUS5

NHS England. Core20PLUS5 (adults) – an approach to reducing healthcare inequalities https://www.england.nhs.uk/about/equality/equality-hub/national-healthcare-inequalities-improvement-programme/core20plus5/

Core20: The most deprived 20% of the national population as identified by the national Index of Multiple Deprivation (IMD) which has indicators accounting for a wide range of social determinants of health.

PLUS: ICS-determined population groups experiencing poorer than average health access, experience and/or outcomes, but not captured in the 'Core20' alone. This should be based on ICS population health data.

Five clinical areas of focus. Governance for these five focus areas sits with national programmes; national and regional teams coordinate local systems to achieve national aims.

3. Chronic Respiratory Disease
A clear focus on COPD driving up uptake of Covid, Flu and Pneumonia vaccines to reduce infective exacerbations and emergency hospital admissions due to those exacerbations

Change NHS: 'the three shifts'

Change NHS. The three shifts https://change.nhs.uk/en-GB/projects/three-shifts

The 10 Year Health Plan will set out how we create a truly modern health service designed to meet the changing needs of our changing population. This will be focused on the three shifts that the government, health service, and experts agree need to happen. This includes:

1. Moving care from hospitals to communities
2. Making better use of technology
3. Focussing on preventing sickness, not just treating it.

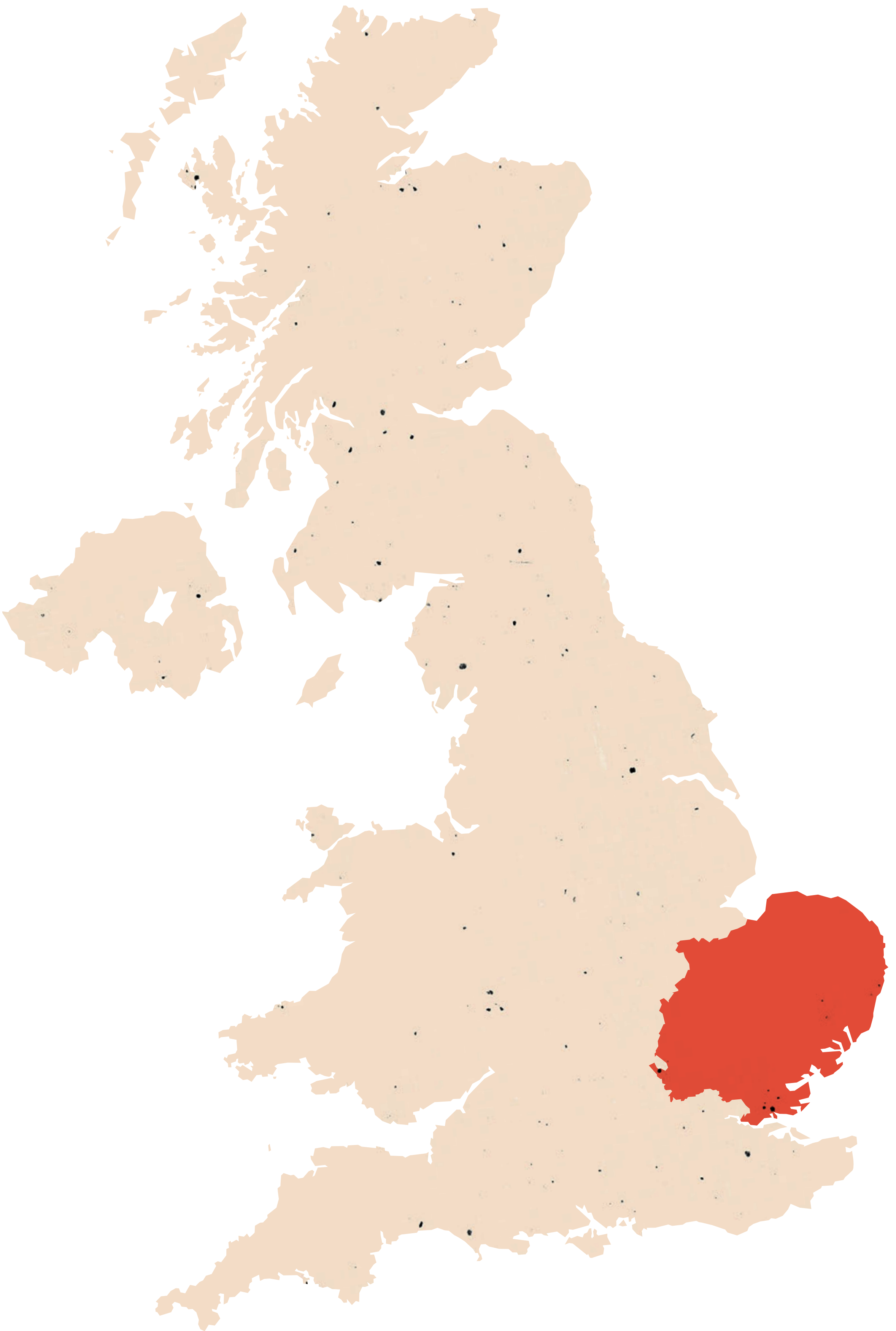
COPD VOICES

Regional profiles

East of England

This well-attended workshop had a range of PwCOPD, from newly diagnosed to those in a severe stage of the condition. They reported marked variations in post-diagnosis care based on their location, highlighting differences in the quality and availability of the COPD services they needed between different areas and providers. Pulmonary rehabilitation appeared to be accessible with most PwCOPD having attended courses.

However, they described logistical access issues, such as transport, parking and mobility challenges, which create significant barriers to seeing their healthcare providers regularly. The financial burden of managing COPD and finding financial support is also a big concern.



Population:

6.4 million

> ‘We have had no GP since lock down just a series of locums where I have to go through my full history every time I go. I was recently sent for a test and spent a week worrying if something was wrong. When I got to the appointment the GP didn’t know why I had been sent for - what a waste of an appointment.’

> ‘Hospice day care has been wonderful. The psychological support had been wonderful and they are more on top of what I need than my GP is.’

> ‘COPD is expensive to have; I wonder how I will manage this winter.’

> ‘My dad had DNR (do-not-resuscitate) on his notes. I knew what that was, no one had told me he was that bad. I fell apart.’

East of England

Local experiences

Diagnosis and information gaps

PwCOPD's experiences of diagnosis in the East of England are mixed. Most people described feeling abandoned, with one person saying his GP treated him like a 'hopeless case'. Many had been diagnosed with conditions like asthma or emphysema and only recently learned about their diagnosis of COPD. A lack of clear, consistent information at diagnosis left many PwCOPD feeling isolated and unprepared to manage their condition.

Access to care and support

PwCOPD report inconsistent quality and availability of services, with significant care disparities between locations. They highlighted how challenging it is to manage comorbidities like heart conditions or cancer alongside their COPD. Fragmented care and poor coordination frustrates PwCOPD who often have to advocate for their own health, with many viewing the role of COPD coordinator as vital. Experiences of secondary care management are more positive compared to general practice, described as lacking awareness of treatment options. PwCOPD highly value pulmonary rehabilitation, however, transport, parking, and mobility issues are barriers to access. The financial impact of COPD is a burden; heating costs and changes to winter fuel payments are causing concerns.

Monitoring and medicines management

PwCOPD feel that rescue medication packs are crucial for managing their symptoms and avoiding hospitalisation. However, many report difficulty accessing these and inconsistencies in prescription and refilling practices. Furthermore, they said that the lack of available GP appointments only increases the risk of admission when they are experiencing an exacerbation.

There is limited advance care planning (ACP) and palliative care discussions and people said this left them unprepared for disease progression. Carers expressed deep concerns about do-not-resuscitate decisions being made without consultation or communication with them. One person had benefited from hospice care, learning more about COPD and completing ACP discussions.

Nobody was aware of biologic treatments and there were concerns about the discontinuation of routine COPD monitoring and that as a result PwCOPD eligible for biologics could potentially be overlooked.

Mental health and social support

Significant psychological toll of COPD. Breathlessness restricts social interactions and daily activities. Peer support and community resources essential for maintaining morale. Some questioned whether COPD treatments impact mental health.

East of England

Local wish list

The top priorities for PwCOPD in the East of England are:

1. **Create a local COPD encyclopaedia.** A centralised, up-to-date and accessible resource provided to everybody at diagnosis, which explains:
    - What COPD is
    - How I can take care of myself.
    - The local COPD care pathway.
    - Treatment options.
    - The role of different healthcare professionals and services in my care.
    - My designated point of contact for my COPD care.
    - Local policy on rescue pack provision and re-dispensing.
    - Pathways for participating in research.
    - COPD-specific resources, e.g. peer group support and recommendations, social networks.
    - Useful sources of local support, e.g. mental health support, benefits and social support.
    - Where to find more information including information/support during exacerbations (e.g. via care navigator or hotline).
2. **A 'COPD Patient Passport'** with key information about their management needs.
3. **Ensure GPs are aware** of the need for prompt investigations and, once diagnosed, the therapeutic options for managing their condition.
4. **An integrated care pathway** to ensure PwCOPD get consistent care, containing explicit roles for the healthcare professionals in COPD management and clearly mapping the explicit links between hospital, community and palliative care services.
5. **Prompt GP access** when a flare up is suspected.
6. **Clarify local policy** on rescue pack provision and re-dispensing.
7. **Better communication and support** on decisions like do-not-resuscitate (DNR).

London

This combined overview of the London workshops included PwCOPD who live in each of the five London ICSs and attend the range of specialist respiratory hospitals within London.

Across the ICBs it was highlighted there was inconsistency in the information provided at diagnosis and the lack of 'joined-up care' between hospitals and community. PwCOPD expressed a much greater need for improved GP awareness of COPD and communication between hospital consultants and GPs.

A lack of management or care plans and routine monitoring meant that any potential problems might go unmanaged until a critical point which impacted on their quality of life and demand on acute services.

Population:

8.8 million

> 'We had no help for 15 or 16 years and then we were referred to pulmonary rehab. It was a turnaround for us. We thought it was a condition you just had to put up with.'

> 'I decided not to go to my son's wedding. I am too embarrassed about gasping for breath and I thought if I was suddenly ill it would ruin the day. I stayed at home and cried.'

> 'It's exasperating when you call your GP and you are caller number 86! I can't do this anymore. I have to get my daughter to ring.'

> 'I need to keep well. I am a carer for my 87-year-old mother and if I can't keep well that impacts on her too.'

London

Local experiences

Diagnosis and information gaps

PwCOPD's experiences of diagnosis in London were mixed depending on their location. There were positive experiences of care in specialist London hospitals; however, many receiving diagnosis and management in primary care were confused and frustrated by insufficient/unclear information. They reported a lack of care coordination between hospital specialists and GPs, who are often unaware of hospital advice. Some people who don't have internet access struggle to find information about COPD and people feel there is not enough COPD-specific information available in general. Those with ongoing access to respiratory consultants and specialist respiratory nurses are highly satisfied with their care.

Access to care and support

Most PwCOPD said they were dissatisfied with GP services, citing challenges booking appointments, dismissive attitudes and staff not recognising the need to be seen/reviewed. Some people rely on external help, such as family or neighbours, to navigate the healthcare system. PwCOPD highly value pulmonary rehabilitation; however, access is inconsistent and not everybody knew how to go about accessing it. Everybody agreed self-management and monitoring as vital, but said the necessary information or tools are lacking. There was significant concern about the post-pandemic discontinuation of annual lung function monitoring.

Monitoring and medicines management

PwCOPD reported that difficulty getting GP appointments, including dismissive receptionists, frequently leads to hospital admission. There is inconsistent access to rescue packs which some people said were deemed unnecessary by their GPs. They described how recurring medication shortages, particularly of inhalers, significantly impacts their ability to self-manage. Hospital discharge is often abrupt with inadequate instructions or follow-up. Nobody was aware of biologics but everyone was interested in learning more about these and participating in COPD research.

Mental health and social support

COPD brings with it isolation, anxiety and depression, which PwCOPD said is only exacerbated by fear of environmental triggers, such as pollution and weather, and the physical limitations they experience. They described how lack of motivation and reduced participation in daily activities diminishes their quality of life.

PwCOPD view peer support groups and counselling services as critical to improving their mental health, but access to these types of resources is inconsistent. Funding is being withdrawn in some areas for walking clubs, peer support groups and Sing 2 Breathe classes which PwCOPD felt will be detrimental to their health.

London

Local wish list

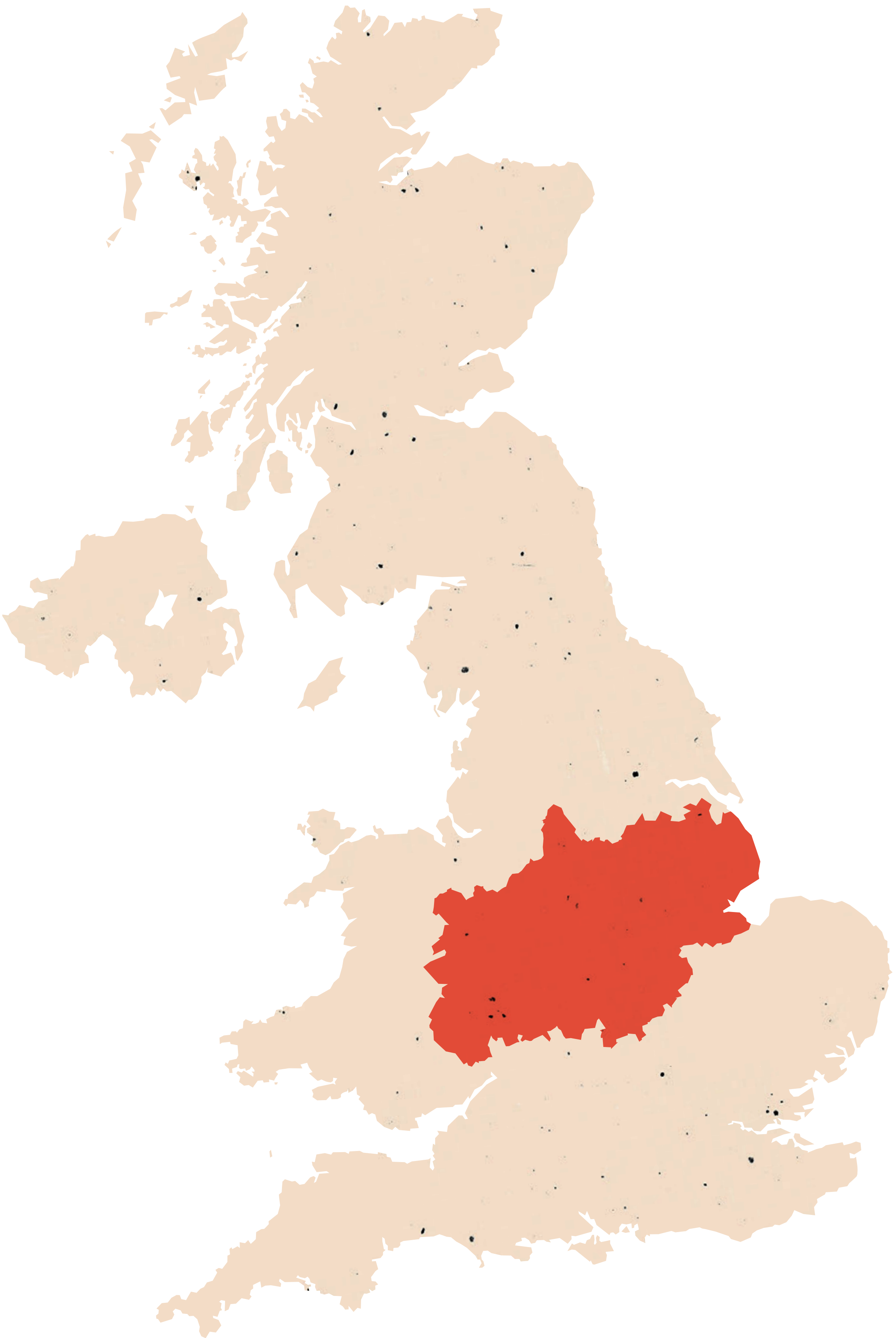
The top priorities for PwCOPD in London are:

1. **Create a local COPD encyclopaedia.** A centralised, up-to-date and accessible resource provided to everybody at diagnosis, which explains:
   - What COPD is
   - How I can take care of myself.
   - The local COPD care pathway.
   - Treatment options.
   - The role of different healthcare professionals and services in my care.
   - My designated point of contact for my COPD care.
   - Local policy on rescue pack provision and re-dispensing.
   - Pathways for participating in research.
   - COPD-specific resources, e.g. peer group support and recommendations, social networks.
   - Useful sources of local support, e.g. mental health support, benefits and social support.
   - Where to find more information including information/support during exacerbations (e.g. via care navigator or hotline).
2. **A 'COPD Patient Passport'** with key information about me and my management needs.
3. **Accessible information in plain English** at diagnosis and contact points for self-help groups.
4. **Training** on how to advocate for my own health.
5. **More information** about home and travel oxygen use.
6. **Follow-up post hospital admission**.
7. **Explicit information** about future potential treatment options including biologics, remote monitoring apps and research trials.
8. **Consistent funding** to maintain important services like support, self-help and exercise groups.
9. **Recognise the unique needs** of young carers provide tailored interventions and support systems. Initiatives like the development of a carer's passport aim to empower carers in balancing their caregiving responsibilities with work commitments, fostering a supportive work environment conducive to their well-being.

Midlands

Language barriers in verbal and written information are a particular challenge for PwCOPD in the Midlands. Alongside the need for better communication with healthcare providers care also needs to be culturally sensitive.

Taking account of cultural nuances across diverse populations has implications for diverse populations across the whole spectrum of health and social care.



Population:

10.8 million

‘One of the most shocking realisations during this journey was the discovery of a DNR (do-not-resuscitate) order on my relative’s notes. A decision made without my knowledge or consent. This disregard for our family’s wishes underscored the need for better communication and involvement of care givers in the decision-making process.’

‘We can’t always be with my sister; we have our own lives to lead, and we don’t want her to be dependent on us. She just can’t grasp what treatment she should take or use the inhaler properly without supervision.’

‘We were invited to a meeting to show us how to use the apps for accessing the GP, prescriptions etc. At the demonstration the apps didn’t work. We came away none the wiser. The only way I can get the prescriptions is to go in and order them.’

Midlands

Local experiences

Diagnosis and information gaps

PwCOPD said one of the main issues, aside from difficulty getting a referral for diagnosis, was lack of information about COPD in the right language which meant there was little in the way of suitable take-home information for many PwCOPD.

Clinical support pathway

PwCOPD were unaware of an actual pathway for COPD but would welcome an outline of the journey. They reported that appointments and investigations are often booked on different days meaning they have to make multiple hospital visits. Another point raised is that not all English words can be accurately translated; sometimes when there is not an equivalent word to express what is meant the content of a communication may be lost.

Access to care and support

PwCOPD described challenges accessing healthcare services and finding GPs increasingly hard to access. Many found it hard to get through on the phone, and if they did manage to get an appointment it was generally with a locum or a nurse and in some cases there was also a three to six week wait.

Monitoring and medicines management

Simple things like using an inhaler were complicated by a lack of understanding about how and when to use them, and which inhaler to use especially for those without literacy. PwCOPD said it is a common assumption that everyone has online access and described feeling fobbed off all the time when they asked for alternative ways to access information and nothing was offered.

A primary caregiver highlighted the language problems that occur when her relative with COPD thinks she is having an exacerbation. If the patient, who lives alone, cannot reach family, she calls an ambulance. Several times when paramedics have arrived she has been unable to communicate with them and therefore taken to hospital and admitted, requiring family to go in to translate. Sometimes however the admission was needless and the breathlessness was provoked by a panic attack.

Mental health and social support

Everybody said that COPD and breathlessness affects their mental health, provoking anxiety, panic attacks and depression. They felt self-help groups support people to develop resilience but language barriers often prevent them from participating. Although many would benefit from self-advocacy training, again language is an obstacle.

Carers

Where a PwCOPD needs to be accompanied to all of their hospital/GP interactions due to language barriers, carers said the impact of this on them needs to be recognised and they need adequate support.

Midlands

Local wish list

The top priorities for PwCOPD in the Midlands are:

1. **Timely GP access** with the option for translation if I need it.

2. **Provide everybody with multilingual**, culturally competent information at diagnosis.

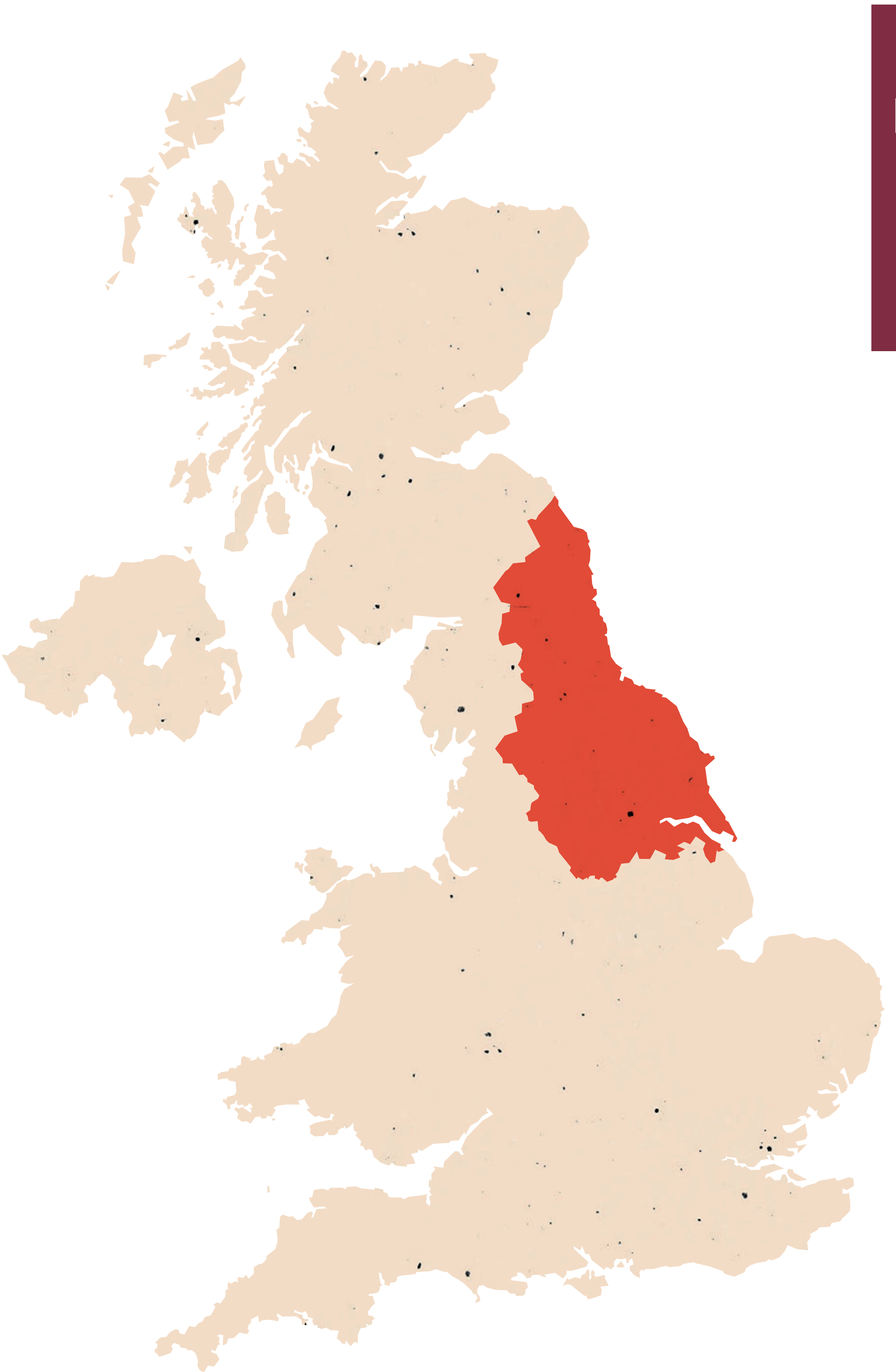
3. **Accessible details** about peer support and self-help groups that accommodate patients and carers from ethnically diverse backgrounds.

4. **Create a local COPD encyclopaedia.** A centralised, up-to-date and accessible resource provided to everybody at diagnosis, which explains:
    - What COPD is
    - How I can take care of myself.
    - The local COPD care pathway.
    - Treatment options.
    - The role of different healthcare professionals and services in my care.
    - My designated point of contact for my COPD care.
    - Local policy on rescue pack provision and re-dispensing.
    - Pathways for participating in research.
    - COPD-specific resources, e.g. peer group support and recommendations, social networks.
    - Useful sources of local support, e.g. mental health support, benefits and social support.
    - Where to find more information including information/support during exacerbations (e.g. via care navigator or hotline).

5. **Ensure that information is shared with carers** if the patient has consented to this.

North East & Yorkshire

PwCOPD in the North East & Yorkshire are struggling with a number of service barriers and as a result many find their condition is not managed as well as it could be. There is high praise for the effectiveness of virtual wards and pulmonary rehabilitation but these services can be difficult to access. Local PwCOPD would like to see a more individualised approach to care that provides consistent, joined-up support focused on optimising health rather than crisis management.



Population:

2.6 million

‘These new drugs they’re bringing out, have they been through NICE yet? It don’t matter how good it is, if it’s dear we won’t get it.’

‘I’ve got a mobile phone from the virtual wards and every night for the trial I filled in how I’d been and it went through to the nurses. It’s been marvellous and the virtual wards are now set up and we have them all the time – the trial was a success.’

‘The respiratory nurses are just brilliant, they get back to you straight away.’

‘We’ve had to take the stair carpet up because so many times I’ve not been able to make it to the toilet and I’ve ruined the carpet. Someone said ‘use a bucket in the day’ or ‘get a commode’, but who would empty it?’

‘I’ve been having problems getting my prescriptions; (the receptionists) say you’ve got to specifically come in to request them but I’m disabled and can’t get out easily. It’s a nightmare.’

‘I moved into a new flat and was so pleased to show it my mum. There was no lift and I’d not appreciated how difficult the stairs would be for her. I had to go and get a chair for her to sit between flights. I was so disappointed I’d caused her so much stress. She could never come again it was too traumatic.’

North East & Yorkshire

Local experiences

Diagnosis and information gaps

PwCOPD said the process to get a diagnosis often spanned years, involving multiple GP visits, citing lack of GP understanding of COPD and difficulty getting referral to a specialist. They described a slow and disjointed diagnostic process, with little communication between GPs and specialists, and a lack of accessible, consistent and clear information which left many feeling isolated and unprepared to manage their condition.

Clinical support pathway

Understanding of the COPD clinical pathway varied. PwCOPD reported inadequate care outside specialist respiratory services, particularly in community settings, and frequently mentioned services only intervene in a crisis leaving routine care and prevention largely unmet. There was frustration with GP annual reviews, which are seen as perfunctory and unhelpful for managing their condition. Both virtual wards and pulmonary rehabilitation are highly valued for their effectiveness, however access was inconsistent with long waiting lists for pulmonary rehabilitation and follow-up care was unavailable. Long-term management is further hindered by a lack of community-based exercise programmes.

Access to care and support

PwCOPD experience prescription issues, such as insufficient quantities of inhalers and inconsistent availability of rescue packs (some people were unable to obtain or renew these). They reported difficulties accessing timely GP care and navigating the healthcare system, describing long waits for home adaptations like stairlifts for example, which only exacerbated the physical and emotional toll of their condition. Simple daily tasks like shopping and cooking are challenging with very limited support for practical needs.

Smoking and vaping

Most PwCOPD we spoke to were current or former smokers. Smoking cessation was acknowledged to be significantly challenging; however, some had successfully cut down, while others had switched to vaping although still had safety concerns. Many felt conflicted between their enjoyment and worries about the health impact of smoking.

Monitoring and medicines management

PwCOPD welcome the development of new treatments like biologics. Those who had participated in research trials were very positive about the care and monitoring they received and reported improved symptoms and fewer exacerbations. However, others were unsure how to participate in trials and so access appears to be patchy.

Mental health and social support

PwCOPD described profound isolation and mental health burden as a result of their condition. Anxiety was heightened among those living alone, who particularly feared acute breathlessness episodes which were likened to 'drowning'. Alongside depression and feeling worthless, PwCOPD described losing their confidence and dignity, for example when losing continence during an attack.

North East & Yorkshire

Local wish list

The top priorities for PwCOPD in the North East and Yorkshire are:

1. **Prompt GP access** when I suspect a flare up.
2. **Ensure GPs are aware** of the need for prompt investigations and, once diagnosed, the therapeutic options for managing my condition.
3. **Ongoing support to maximise my wellbeing**, including:
   - Follow-up after hospital stays.
   - Smoking cessation support.
4. **Create a local COPD encyclopaedia:** a centralised, up-to-date and accessible resource provided to everybody at diagnosis, which explains:
   - What COPD is.
   - How I can take care of myself.
   - The local COPD care pathway.
   - Treatment options.
   - The role of different healthcare professionals and services in my care.
   - My designated point of contact for my COPD care.
   - Local policy on rescue pack provision and re-dispensing.
   - Pathways for participating in research.
   - COPD-specific resources, e.g. peer group support and recommendations, social networks.
   - Useful sources of local support, e.g. mental health support, benefits and social support.
   - Where to find more information including information/support during exacerbations (e.g. via care navigator or hotline).

South East

The well attended meetings in the South East highlighted the variable support for PwCOPD, with some saying they had received minimal information about their condition while others were given detailed explanations. They raised issues that include diagnosis delays, challenges accessing GP appointments and difficulties obtaining timely medication and treatments.

The conversation highlighted the need for better communication and continuity of care, particularly with GPs. PwCOPD also emphasised the importance of mental health support and the challenges of navigating benefits and financial assistance, and a discussion about advanced directives underlined the importance of planning for future healthcare needs.

Population:

9.3 million

‘We always used to have a named doctor you saw, but that’s gone now and every time I see one I have to go through the whole history again. There’s no continuity and no familiarity of your circumstances like there used to be.’

‘I’ve had COPD ten years but I’ve never smoked, but my dad used to smoke like a train. They say you can’t get COPD if you don’t smoke but I think I got it from him.’

‘My medical centre has a dedicated asthma nurse and she sees me and is very good.’

‘I’ve been diagnosed four years and have inhalers. When I rang for the repeat prescription I was told I had to see the doctor before I could have them re- prescribed; however, I couldn’t get an appointment with him. After repeated calling for an appointment I had to ring 111 for them to get the prescription sanctioned for me. What a waste of NHS time... Two years later I still haven’t had a check up with the doctor.’

● ○ ○

South East

Local experiences

Diagnosis and information gaps

The information PwCOPD received at diagnosis in the South East varied. People diagnosed 10–20 years ago said they were given no information, regardless of where diagnosis was made, whereas those diagnosed in the last three years by a hospital consultant were given good information and were very well supported by the hospital respiratory services. However, there remained a lack of information and follow-up in the community. This lack of accessible, consistent and clear information at diagnosis left many feeling isolated and unprepared to manage their condition.

Access to care and support

PwCOPD were dissatisfied with GP contact and care, saying GPs needed more COPD knowledge and better communication with hospital consultants. Everybody reported feeling GPs did not believe them about symptoms and were generally dismissive of any problems. They described problems making contact with GPs to get an appointment or review which could only be made on by phone or e-consult. A third of the PwCOPD we spoke to did not have internet access.

Almost everybody could access pulmonary rehabilitation courses and said they were very beneficial. The Breathe Easy group is highly regarded not only for the breathing exercises it offers, but as a source of information and opportunities to develop friendships and peer support.

There were concerns about advanced and end of life care planning, particularly from carers, who described their experiences of being seemingly ‘coerced’ into making and retaining do-not-resuscitate orders after the person they cared for had recovered from an exacerbation.

Monitoring and medicines management

One PwCOPD said he had no future treatment plan and felt ‘written off’ by doctors. Others wanted ongoing support rather than annual reviews alone so that they would know if they might be eligible for new treatments. PwCOPD wanted more contact and communication with healthcare professionals. They welcomed more treatment choices including biologics but stressed the need for informed consent, education, and timely access once approved. Some questioned if NICE would make biologics available for the treatment of COPD.

Mental health and social support

PwCOPD described the significant psychological impact of their condition, including isolation and anxiety. They also expressed significant anxiety about the challenges accessing financial assistance and understanding eligibility criteria for benefits.

South East

Local wish list

The top priorities for PwCOPD in the South East are:

1. **Create a local COPD encyclopaedia.** A centralised, up-to-date and accessible resource provided to everybody at diagnosis, which explains:
    - What COPD is
    - How I can take care of myself.
    - The local COPD care pathway.
    - Treatment options.
    - The role of different healthcare professionals and services in my care.
    - My designated point of contact for my COPD care.
    - Local policy on rescue pack provision and re-dispensing.
    - Pathways for participating in research.
    - COPD-specific resources, e.g. peer group support and recommendations, social networks.
    - Useful sources of local support, e.g. mental health support, benefits and social support.
    - Where to find more information including information/support during exacerbations (e.g. via care navigator or hotline).
2. **A centralised person/information point,** such as a care navigator or directory where I can get information about COPD and support, particularly during exacerbations, and details about how to access local sources of help like benefits and social support.
3. **Ensure GPs are aware** of the need for prompt investigations and, once diagnosed, the therapeutic options for managing my condition.
4. **An integrated care pathway** for a more individualised, patient-focused approach that clearly maps the explicit links between hospital, community and palliative care services and ensures PwCOPD get consistent care and communication.
5. **Provide me with information** about future potential treatment options for COPD, including biologics, and opportunities to get involved in research trials.
6. **Regular training** on the correct inhaler techniques.
7. **Clarify local policy** on rescue pack provision and re-dispensing.
8. **Access to high-quality follow-up care** for true long-term recovery after hospitalisation.
9. **Expand counselling services** to address COPD-related stress.
10. **Better communication and support** on advance care planning (ACP) and decisions like DNR (do-not-resuscitate).

North West

This diverse group of PwCOPD felt that the social determinants of health have a significant impact on how their health is managed. They said issues like low income, unemployment, job insecurity, working conditions and low educational attainment affected their health and self-value and often left them feeling ignored or that they didn't matter.

Everyone had been admitted to hospital with a flare-up brought about by delays in access to primary care, and said their health was put back 'on track for several months' once they were seen in hospital.

Population:

7.4 million

'I could be sat at home and breathless and not know what to do. I have no understanding of what to expect. How can I look for things to support me when I don't know what to look for? I've heard about stuff like pulmonary rehab in this discussion that I've never heard of before.'

'I've enrolled for research trials to get better monitoring. They look after you too!'

'I don't really have friends anymore I don't have anything to say to them as I don't go anywhere. They don't want to know about my health all the time so I've stopped ringing them in case they say 'that miserable woman's rung again'!'

'No-one thinks about the environmental issues that might have affected me growing up: damp house, smoky environment with the factories. Yes, I smoked then ,but there were other factors that I think affected me.'

'I feel we are given a label of COPD and thrown away because there is nothing that can be done. There is stigma around the condition everyone assumes you are a smoker and I was but I also lived in an industrialised area with smoke from factories. I worked in the steel works from being 16 breathing in fumes. My mum was a single parent we had a poor diet. I think these things contributed.'

North West

Local experiences

Diagnosis and information gaps

The PwCOPD we spoke to were diagnosed 14–20 years ago; two were identified via workplace lung screening and the rest by GPs. They often attributed symptoms to smoking and were unaware of the condition's severity. Lack of information at diagnosis had left them feeling isolated and unsure how to self-manage. Age-related factors contribute to a perception of abandonment and neglected follow-up care, and some feel GPs view them as 'hopeless cases'.

Access to care and support

PwCOPD reported fragmented care in the North West, with frequent GP and staff changes disrupting the continuity of their care. They said poor communication between hospitals and GPs leads to inconsistencies and gaps in support. Since the shift towards virtual consultation post-pandemic, they feel it has become more difficult to address issues related to COPD with their GP. Annual lung health checks, which had included spirometry, are no longer offered, leading to concern about how their disease progression will be monitored. Two PwCOPD said they get regular monitoring from respiratory teams as part of clinical trials, whereas the others who rely on GPs are dissatisfied with lack of expertise and care continuity. Two PwCOPD were non-smokers and were keen to highlight that although many PwCOPD do not have a history of smoking, in their experience as non-smokers they were not allowed to be included in research. Pulmonary rehabilitation resources are perceived to be overstretched and nobody had accessed this service despite some PwCOPD having referrals dating back years. In terms of local support, nobody was aware of the existence of any groups for PwCOPD like Breathe Easy.

Monitoring and medicines management

PwCOPD experience significant difficulty getting GP appointments during exacerbations which frequently leads to hospital admission. In their view, hospital care is not only beneficial for treating exacerbations, but for improving their overall health through review and adjustment of their medication. Only three people had rescue packs, the others were unaware of their availability. Many PwCOPD were concerned that symptoms of other health issues can be misattributed to COPD. They described how addressing unrelated factors, such as allergies, significantly improved their condition – underscoring the need for comprehensive assessments. Nobody was aware of biologics and they were concerned that, with such infrequent COPD consultations, GPs may not recognise when these treatments would be appropriate. They also questioned the effectiveness of health questionnaires, which they felt did not lead to actionable outcomes.

Mental health and social support

PwCOPD described the anxiety and depression they experience and how their physical limitations erode confidence and lead to social isolation. These difficulties are exacerbated by worries about infection exposure, body image and needing to plan activities meticulously. Describing the effect of age-related stigma and socioeconomic factors (e.g. low income, job insecurity) on their health and self-worth, there was a strong feeling that factors such as industrialisation of the local area, pollution, poor diet, and damp/mouldy housing had contributed to their poor lung health.

North West

Local wish list

The top priorities for PwCOPD in the North West are:

1. **Regular COPD monitoring** to ensure my treatment is optimised:
    - Reinstate annual lung health checks.
    - Enhance GP and practice training on COPD-specific care and triggers for flare-up.
    - Develop clear pathways for access to biologics so that my GP understands if this might be a treatment option for me.
    - Improve the communication between GPs and hospitals to ensure I get continuity of care.
2. **Create a local COPD encyclopaedia:** a centralised, up-to-date and accessible resource provided to everybody at diagnosis, which explains:
    - What COPD is.
    - How I can take care of myself (e.g. a self-management checklist).
    - The local COPD care pathway.
    - Treatment options.
    - Advice and support on how the environment can impact COPD e.g. hot weather, pollen count etc
    - The role of different healthcare professionals and services in my care.
    - My designated point of contact for my COPD care.
    - Local policy on rescue pack provision and re-dispensing.
    - Pathways for participating in research.
    - COPD-specific resources, e.g. peer group support and recommendations, social networks.
    - Useful sources of local support, e.g. mental health support, benefits and social support.
    - Where to find more information including information/support during exacerbations (e.g. via care navigator or hotline).
3. **Access to the support I need,** including:

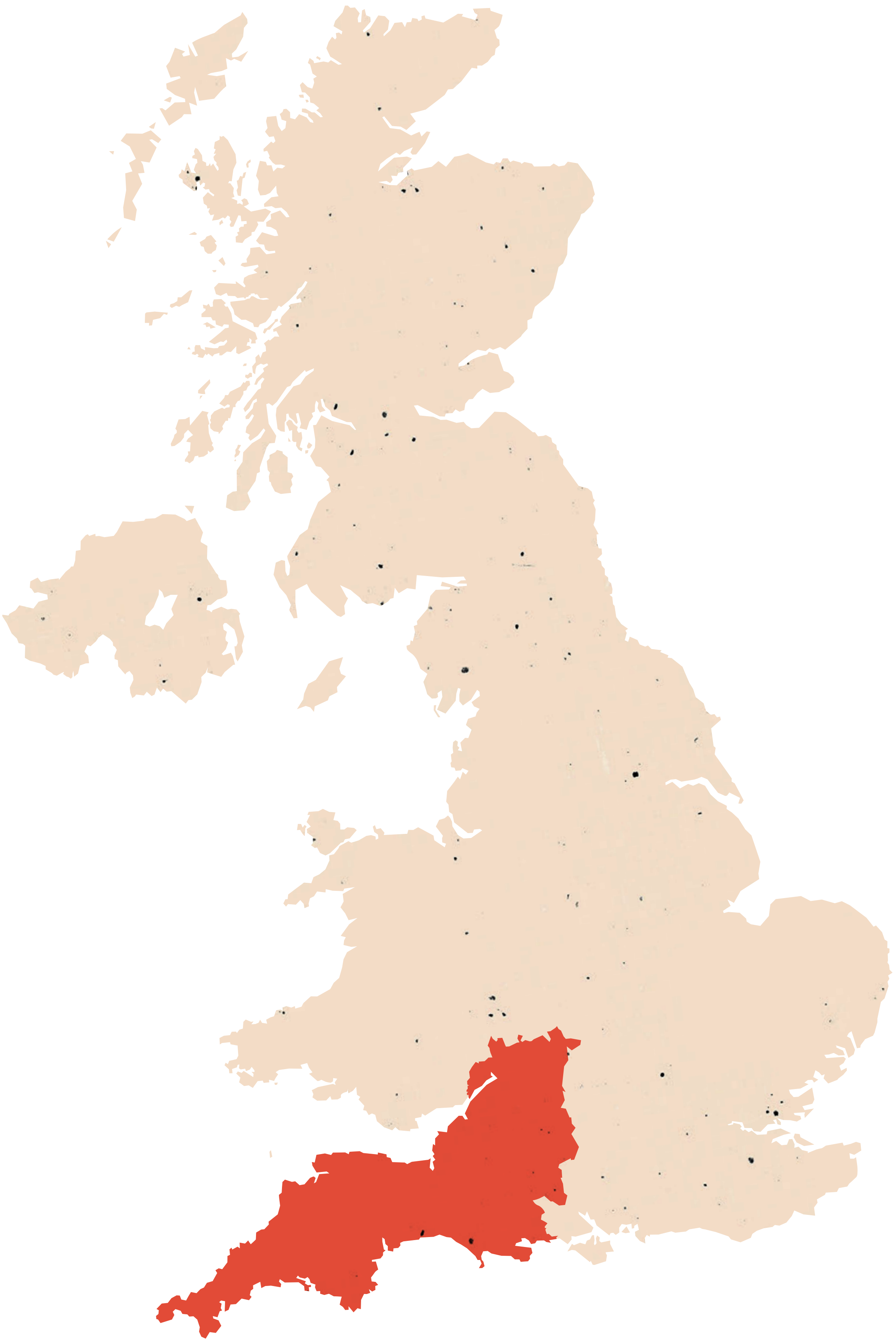
    Mental health services tailored to address the anxiety, depression and social isolation that come with COPD.

    Expanded access to pulmonary rehabilitation and local peer support groups to foster community and reduce loneliness.

South West

The demographic landscape in Somerset where this workshop was conducted shows a significant ageing population, with nearly 25% of residents aged 65 or older, and a notable increase in those over 75. This ageing trend correlates with a rise in chronic conditions like COPD.

The county's socioeconomic disparities further complicate access to quality healthcare, with many residents living in the most or least deprived areas of England.



Population:

5.7 million

'I don't get any annual checks, and no one does spirometry testing on me anymore.'

'Why wasn't my oxygen levels checked before? If I'd been followed up by my GP or practice nurse properly, this (oxygen therapy) would have helped.'

'I have waited nine months already to be assessed for a stair lift. I want to be independent but I need to be assessed for things that will help me.'

'Pharmacy has swapped my Ventolin inhaler, it's no use now.'

'I ring for a GP appointment; I may as well forget it; they give me one in two weeks – if I am bad, I go to A&E at least I get seen there.'

'Nothing is going on in Somerset for COPD; surely there are groups I could go to, but where are they? I don't have internet – how do I find out? Everything is online these days; what about people like me that can't afford a phone?'

'I don't think my inhaler is effective anymore; we get a cheaper version of Ventolin and it's no good.'

'Initiatives like the development of a carers passport could really help in balancing caring and work commitments.'

South West

Local experiences

Diagnosis and information gaps

Many PwCOPD reported delayed diagnoses, often following years of symptoms such as persistent coughs and repeated respiratory infections. They described inadequate initial interactions with healthcare providers, with symptoms that were dismissed or misattributed to less serious conditions. These accounts reveal a pervasive issue: delayed diagnoses where outcomes may have been improved with more attentive and informed primary care.

Clinical support pathway

PwCOPD found themselves battling with not just the physical symptoms of their condition, but also the systemic barriers that make the clinical support pathway hard to negotiate. PwCOPD reported a very concerning shift towards virtual consultations and reduced availability of monitoring services like spirometry tests. Lung health was no longer monitored in general practice with reviews focussing mainly on weight, blood pressure and cholesterol levels.

Access to care and support

Many felt excluded from care and support especially those without internet access or digital literacy. Several PwCOPD living in the most deprived areas of Somerset had no digital access or transport and had difficulty accessing their GP or support groups where they might gain peer support. This highlights the broader issue of accessibility, where digital divides leave the most vulnerable patients disconnected from vital resources.

Monitoring and medicines management

PwCOPD universally said they are concerned about the effectiveness of their medication and substitutions that have been made without their consent following the withdrawal of Ventolin prescriptions locally. They feel these substitutions not only impact symptom control but undermine patient trust in their prescribed treatments.

Mental health and social support

PwCOPD felt they could benefit immensely from peer support and community-based interventions and highlighted the value of local support groups, such as walking and singing classes, which not only offer physical benefits but also a sense of community and shared experience. Access to these groups is often limited by cost, availability and lack of information, which suggests a need for more robust and accessible community support options, potentially through 'exercise on prescription' or local health initiatives.

Pulmonary rehabilitation

PwCOPD highlighted the crucial role of pulmonary rehabilitation (PR) in assessing, managing and improving their condition. One person said it was only by doing the walk tests when she attended PR that her additional need for oxygen during exertion was identified. Access to PR appeared to be variable depending on the location and referral process and with long waiting times. One person reporting hearing that 1,000 people are on the waiting list, while another said there were only four people at her class. Several reported being denied referral for PR. Some PwCOPD expressed concerns about how accessible support groups or PR (if they were offered it) would be because they would not be able to afford the travel involved.

South West

Local wish list

The top priorities for PwCOPD in the South West are:

1. **Ensure GPs and nurses are trained about COPD** and are aware of the need for prompt investigations and, once diagnosed, the therapeutic options for managing my condition.
2. **Ensure there is an integrated care pathway** that outlines the care and support I will need so that I understand the COPD journey and so that my GP and practice nurse do too.
3. **Prompt GP access** when I suspect a flare up.
4. **Increase the availability of pulmonary rehabilitation** to keep me well and opportunities like Sing 2 Breathe to get together with other PwCOPD.
5. **Provide me with information** about future potential treatment options for COPD, including biologics, and opportunities to get involved in research trials.

COPD VOICES

In collaboration with

KING'S College LONDON

Published April 2025

Graphic design: Matt Whitehead hello@mattwhitehead.com