COPD in the UK: Delayed diagnosis and unequal care

Executive summary and recommendations

November 2022

Chronic obstructive pulmonary disease (COPD) is the name for a group of lung conditions which make it more difficult to breathe air out of the lungs, due to a permanent narrowing of the airways and destruction of lung tissue. COPD includes long-term (chronic) bronchitis and emphysema. In the UK there are 1.4 million people with a diagnosis of COPD. Each year around 30,000 people in the UK die from COPD. In terms of diagnosed cases, this makes COPD the second most common lung disease in the UK, after asthma.[1] Around 2% of the whole population (4.5% of all people aged over 40) live with diagnosed COPD.[2]

Asthma + Lung UK has gathered evidence[3] of patient experiences of COPD care through our COPD Patient Passport, a checklist for people with COPD to ensure they are receiving the best care.[4] Building on this and our 2021 survey, Asthma + Lung UK conducted this survey of over 6,500 people with COPD between January 2022 and April 2022.

One year on from our first report in 2021,[5] significant issues with delays to diagnosis and the quality of COPD care identified then have not been resolved and, in many cases, have deteriorated. Our survey also highlights the disproportionate impact of inequalities on people with COPD.

Delays to diagnosis

- Even before the COVID-19 pandemic there were already problems with diagnosis and care for people with COPD. Available estimates of the proportion of people with COPD who are undiagnosed vary between about half[6] to as much as two thirds.[7] Available evidence from NICE published in 2011, and updated in 2016, indicates that there could be as many as two million people in the UK with undiagnosed, and therefore untreated, COPD.[8] More research is needed to update these figures.
- Shockingly, **12.4% of respondents (one in eight) waited more than 10 years for a diagnosis**.
- **Almost a quarter of people (nearly one in four) surveyed are waiting five years or more for a diagnosis.**
- More than a third (34%) of people surveyed said they were unable to recognise the signs of COPD, and around 1 in 4 (23%) said they were misdiagnosed as their doctor thought they had a chest infection or cough.
- Other key problems included access to care, with 1 in 4 (26%) people saying they couldn't get an appointment and 1 in 5 (21%) being unable to access key tests, such as spirometry, which are essential for an accurate diagnosis.

Quality of care

Five fundamentals of COPD care:

- Offer treatment and support to **stop smoking**
- Offer **pneumococcal (pneumonia) and influenza vaccinations**
- Offer **pulmonary rehabilitation** if indicated
- Co-develop a personalised **self-management plan**
- Optimise treatment for **co-morbidities**
- Treatments and plans should also be revisited at every review.[9]

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

- **Only 21.6% had received spirometry in the last 12 months,** despite guidance published in April 2021 (a year before our survey closed) indicating that spirometry is safe.[10]
- **UK-wide, those that had received the full package of care (all five fundamentals[11] outlined above) has dropped from 24.5% to just 17.6%, a reduction of 6.9%.**
- **This means less than a fifth of people with COPD surveyed received recommended levels of care.**
- **Overall levels of five fundamentals (5F) care provision have dropped in every nation,** most prominently in England **(from 26% in 2021 to 18.4% in 2022)**.
- Our survey also shows drops in several of the individual fundamentals, including smoking cessation services (down 1.1%), provision of key vaccines (0.7% for flu and 2.3% for pneumococcal (pneumonia) vaccines), and pulmonary rehabilitation (PR) (down 4.2%[i]), as well as the number of people who have co-developed their personalised self-management plan (down 2.4%).

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

We know that those that receive the five fundamentals of care have better outcomes, such as fewer exacerbations and improved self-management.[12] There is also a related impact on NHS resources: providing good basic care to people with COPD may prevent hospital admissions later, saving the NHS money in the long term.

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

Impact of health disparities

Poorer people are more likely to develop COPD than others, and those with COPD who are poorer are particularly struggling. Poorer people with COPD have more exacerbations,[13] and the poorest people with COPD are being left further behind in terms of the care that they are receiving.

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

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

Headline survey findings

Chapter 1: The journey to diagnosis

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

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

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

Chapter 2: Quality of care

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

- **Quality of care has plummeted for people with COPD:** levels of routine care have dropped lower than last year's levels.
- **UK-wide, the number of those that had received the full package of care (all five fundamentals[14] outlined above) has dropped from 24.5% to just 17.6%, a reduction of 6.9 percentage points.**
- This means less than a fifth of people with COPD surveyed received recommended levels of care.
- **Overall levels of five fundamentals (5F) care provision have dropped in every nation**, most prominently in England (from 26% in 2021 to 18.4% in 2022).
- **Only 21.6% had received spirometry in the last 12 months,** despite guidance published in April 2021 (a year before our survey closed) indicating that spirometry is safe.[15]

People who receive all five core elements of COPD care have better outcomes, fewer flare-ups and a better knowledge of how to manage their condition.[16] Those who are not receiving the 'five fundamentals'[17] of COPD care are missing out on the best care, which could in turn impact the severity and management of their condition.

Chapter 3: The need to address health inequalities

- Poorer people with COPD have more exacerbations.[18]
- The poorest people with COPD are being left further behind.
- **Someone from the poorest 10% of households is more than two and a half times more likely to have COPD than someone from the most affluent 10% of households.**

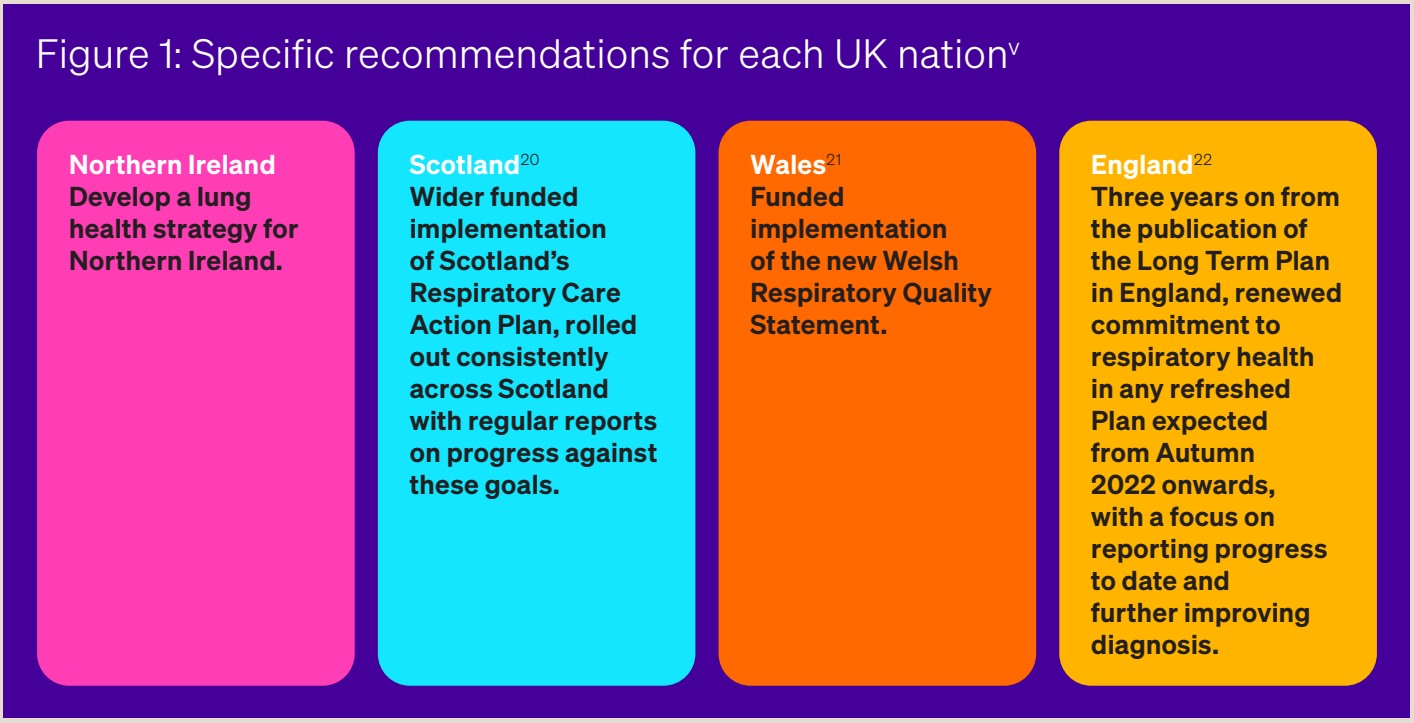
Policy recommendations

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

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

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

Figure 1: Specific recommendations for each UK nation[v]



Specific recommendations for clinical education and practice

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

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

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

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

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

- **Ensure evidence of COPD found at Targeted Lung Health Checks (TLHCs) is not ignored.** We hope to see the inclusion of spirometry as the optimum protocol and pathway is determined for the implementation of screening across the UK.[23]

Renewed provision of care levels prescribed in the NICE clinical guidelines[24] is needed.

- All five fundamentals of COPD care[25] should also be made a core part of undergraduate and postgraduate medical training.

- Ensure all those who could benefit from access to pulmonary rehabilitation (PR) are able to access it.

- Smoking cessation: ensure all the proposals in the Khan review[26] are followed, especially funding for comprehensive stop smoking services.

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