Failing on the fundamentals

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

Executive Summary & Recommendations

November 2021

Chronic obstructive pulmonary disease (COPD) is the name for a group of lung conditions that cause breathing difficulties and a permanent narrowing of the airways. It is the fifth most common cause of death in the UK, resulting in 30,000 deaths per year[1]. More than 1.3 million people in the UK have a diagnosis of COPD and it is estimated that at least a similar number of people have the condition but are as yet undiagnosed[2]. In the absence of treatment those without a diagnosis are at risk of deteriorating health and quality of life, with later diagnosis linked to higher levels of COPD exacerbations and a greater chance of dying from the disease[3].

Thousands missing out on diagnosis

The BLF conducted this survey of over 8,000 people with COPD between December 2020 and May 2021. Even before the pandemic, it is clear from the responses that many people with COPD had experienced unacceptable delays before a diagnosis was made. During this period, the impact of COVID-19 considerably worsened people's daily lives, their chances of being diagnosed, and the level of care they received. Recent government figures found that diagnosis rates – which were already far too low – plummeted even further. In 2020 there was a 51% reduction in COPD diagnosis compared to 2019, meaning that around 46,000 people missed out on a diagnosis in England alone, a much higher drop than seen for comparable conditions, such as diabetes[4].

As of November 2021, diagnostic tests such as spirometry have not yet properly resumed, making it likely that a further 46,000 people in England may have gone undiagnosed in 2021. While rates of cancer diagnosis are already up to, and in some areas better than pre-pandemic levels[5], there is no dedicated plan to address the huge backlog in respiratory care. In all four nations, we want to see respiratory plans address this issue urgently.

75% of people with COPD are not receiving basic care

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

Isolated and left behind

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

Headline survey findings

COPD diagnosis – delays and missed opportunities

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

COPD care – low standards and huge variations

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

What does it mean to live with COPD?

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

Perceptions of COPD – misunderstood and left behind

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

The full report into this survey can be found **here**.

Recommendations

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

Rapidly commit funding for national health services to get lung health strategies back on track and tackle the respiratory backlog. While respiratory conditions are supposedly a clinical priority, this does not seem to be the case in practice, and we need to see ambitious targets for improving COPD prevention, diagnosis and care. In England and Scotland this means getting back on track with the respiratory ambitions set out in the NHS Long Term Plan and the Respiratory Care Action Plan respectively, and national health services must work with clinicians and patients to develop a new Respiratory Health Delivery Plan in Wales and a Lung Health Strategy in Northern Ireland as an urgent priority.

To improve COPD diagnosis:

UK wide recommendations:

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

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

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

As the landscape in England is changing significantly we have some specific recommendations:

Questions on respiratory health should be made a mandatory part of the NHS Health Check, to help identify the many undiagnosed cases of COPD. This should be supported by better compliance with NICE guidance on assessing patients presenting with COPD symptoms and referrals for spirometry where necessary.

Community Diagnostic Centres (CDCs) must be rolled out at the scale recommended in the Richards Review – 3 hubs per million people. These need to be supported by multi-year investment from the Department of Health and Social Care and clearer guidelines from NHS England on how CDCs should operate, so that Primary Care Networks can get them up and running as soon as possible.

In the meantime, **NHS England must ensure quality assured spirometry testing is being delivered in primary care**. People with COPD cannot afford to keep waiting for a formal diagnosis and see their symptoms and wellbeing deteriorate until CDCs are established. Unless spirometry and other diagnostic tests are restarted in general practice, the diagnostic backlog risks overwhelming CDCs as soon as they are established. While guidance has been published on how to conduct spirometry in a COVID-safe manner, this appears to have made little difference and there is a clear need for NHSE to intervene.

The NHS England Long Term Plan includes **a commitment of £200,000 for training health care professionals involved in spirometry testing**, which has been put on hold indefinitely because of COVID-19. We want to see this unfrozen and used as soon as possible as part of the effort to address the significant backlog in respiratory care.

To improve care for people with COPD:

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

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

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

To reduce health inequalities:

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

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

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

Local health services should also ensure hospitals are delivering the 'Ottawa Model' for smoking cessation to support people admitted to quit.

References

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4. Department for Health and Social Care and the Office for National Statistics. 2021. Direct and Indirect health impacts of COVID-19 in England – short paper. Department for health and Social Care. Accessed **here** (October 2021)
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