**The Health Foundation’s COVID-19 impact inquiry: written submission from Asthma UK and the British Lung Foundation**

**Briefly describe the aims and questions covered by the evidence that you would like to submit.**

Asthma UK and the British Lung Foundation’s submission to the Health Foundation’s COVID-19 inquiry aims to contribute the experiences of people with a lung condition during the pandemic and the impact it has had on them, as outlined by the evidence that we have submitted.

1. What was the impact of people’s existing health status on their experience of COVID-19?

Around 12 million people in the UK are affected by a lung condition, including asthma, COPD and pulmonary fibrosis. People with lung conditions have been told they are at an increased risk of developing severe symptoms or of dying if they contract COVID-19, meaning they are strongly advised to observe strict social distancing.[[1]](#footnote-2) Over one million people across the UK with a severe respiratory condition were also deemed by the government as ‘clinically extremely vulnerable’ (CEV) and advised to shield.[[2]](#footnote-3)[[3]](#footnote-4)

Despite good intentions, the shielding process was stressful and chaotic for people with lung disease. There were issues in identifying people recommended to shield. This led to delays and a gap of several weeks between shielding being announced and a final list developed of everyone who needed to shield. This could have left extremely vulnerable people at risk of exposure to COVID-19.

Shielding has had a considerable impact on people with a severe respiratory condition who are deemed as CEV. Although shielding is no being longer advised, it’s important to know that many people continued shielding unofficially and without support. Our latest research has indicated that 17.2% of people with lung disease who are CEV have been shielding since the start of lockdown in March.[[4]](#footnote-5)

Of those who have been shielding, survey respondents listed anxiety about catching coronavirus as their top concern (29%), followed by the impact on mental health (23.8%) and uncertainty of the future (14.9%), when asked about the main challenges of COVID-19.[[5]](#footnote-6) These concerns, as well as shielding and other lockdown restrictions, are impacting the physical fitness of those who are CEV, with over half of people (53%) telling us that they are less fit than at the start of lockdown.[[6]](#footnote-7) Our survey results also reveal the significant impact the pandemic has had on mental health. This has been backed up by the huge influx of calls to our helplines from people with respiratory disease who are isolated, desperate for information and whose mental health has taken a huge hit.

1. How did people’s individual, social and economic circumstances affect their experience of COVID-19?

Many people with a lung condition have faced financial hardship during COVID-19, with more than a third reporting a drop in their income due to coronavirus, and those on lower incomes were affected to a greater extent.[[7]](#footnote-8) 50% of those with a household income of £20,000 or lower told us their income had dropped since the start of the pandemic.[[8]](#footnote-9)

Lung disease is strongly linked to poverty and disadvantage. People in the poorest areas of the country are more than twice as likely to die from lung cancer or COPD than those in the richest areas.[[9]](#footnote-10) They are also more likely to suffer from uncontrolled asthma, which is fuelled by difficulties affording prescription charges, resulting in worse asthma control and potentially life-threatening asthma attacks.[[10]](#footnote-11)[[11]](#footnote-12) People on lower incomes often have inferior access to care and treatment to help manage their illness.

As outlined in the first question, shielding can be a huge burden for many people so it’s imperative that social distancing measures are taken seriously to stop the spread of the virus. Asking people to shield again if virus transmission becomes out of control would have significant consequences.

When we asked people with a lung condition about how closely they thought the general public were following the rules, 76.4% of respondents said 'not that well' or 'not well at all', contributing to further anxiety.[[12]](#footnote-13) The general population need to take social distancing seriously and stop the spread of the virus, so vulnerable people aren’t forced to shield again. It’s unacceptable to expect everyone who is ‘vulnerable’ to lock themselves away while the rest of us live normally – that’s not the kind of society we aspire to be.

A large proportion of people with lung disease are used to minimising contact with other people during the winter months because they are more vulnerable to respiratory infections. During the COVID-19 pandemic, the general public have been able to understand what this feels like and the effect it can have on mental and physical health. Moving forward, if we can capture this empathy then that will be really valuable for society.

1. What was the impact of government and societal response to the pandemic on people’s health eg lockdown?

The COVID-19 pandemic has had an enormous impact on the care of people with lung disease, with the NHS suspending many of its services during lockdown.[[13]](#footnote-14) People with lung conditions have also delayed seeking treatment due to worries about putting pressure on the NHS, and fears about the spread of coronavirus during lockdown. Our survey of over 8,000 patients with lung disease found that over a third of people had their care delayed or cancelled during lockdown.[[14]](#footnote-15) This could be a cancelled annual review, a delayed appointment to see a specialist, or not being referred for an essential test. Also, a quarter of people experienced worse symptoms as a result of care being delayed or because they avoided seeking treatment – due to worries about putting pressure on the NHS and fears around the spread of COVID-19.[[15]](#footnote-16)

Data analysis from The Taskforce for Lung Health found that in April alone, referrals for urgent care for people with lung conditions dropped by as much as 70% during lockdown. An average of over 3,000 patients per week have missed out on a referral for specialist care, treatment or diagnosis in England.[[16]](#footnote-17) Overall, 85% of people have experienced some sort of delays or disruptions to their care.[[17]](#footnote-18) Furthermore, we have continued asking people with lung disease about interruptions to their care since July, when, in theory, services should have been getting back to normal, and 23.7% have had their care delayed or cancelled since July.[[18]](#footnote-19)

Our recent report, *Recovery and Reset for Respiratory*, provides a series of recommendations for how services for patients with lung disease can be restored and improved.[[19]](#footnote-20)

* GP practices should offer a choice of video, phone, face-to-face and digital options for carrying out annual reviews with patients, considering patient preferences
* GP practices should identify patients at greatest risk through risk stratification and invite them to attend a review
* NHS England and the governments in Scotland, Wales and Northern Ireland should each develop a communication plan for patients, encouraging everyone to know who they should contact if they have new or worsening respiratory symptoms
* Patients who have been diagnosed without use of appropriate lung function tests must have their diagnosis confirmed with tests as soon as possible
* Commissioners should maintain new ways of delivering care and treatment which benefit patients

Our post-COVID HUB also found that people recovering from mild-moderate COVID-19 are struggling for weeks with symptoms, raising concerns that there is not adequate support for people who have not been in hospital with the illness.[[20]](#footnote-21) Of those surveyed, 92% are struggling with breathing problems, 83% from extreme fatigue and 46% with sleep problems after having COVID-19 symptoms.[[21]](#footnote-22) These symptoms are affecting people’s day to day lives, with three quarters of people most affected by breathing problems saying the symptoms ‘often’ or ‘always’ interfere with daily activities.[[22]](#footnote-23) Long Covid is also taking its toll on people’s mental health. Over half of people surveyed say they do not feel they can cope well, with some people even suffering from symptoms of post-traumatic stress disorder.[[23]](#footnote-24)

Furthermore, many people with a lung condition reported stigma about not being able to wear a face mask, as their use became more widespread and mandated in public areas across the UK. Certain groups of people were not advised to wear face masks, including people with severe respiratory conditions such as severe asthma and COPD, who find that using a face mask makes it hard for them to breathe.[[24]](#footnote-25) When we asked people with a lung condition whether wearing a face mask increases their difficulty to breathe, over half said they agreed or strongly agreed that it would.[[25]](#footnote-26) However, a lot of people and businesses are not aware that face mask exemptions are in place and this has not been communicated as clearly as it could by government, leading to people being challenged in public

1. How has the government and societal response affected the social and economic circumstances that are likely to have implications for people’s long-term health?

Since the COVID-19 pandemic, some NHS funding formerly allocated for taking forward respiratory commitments in the Long Term Plan has been put on hold indefinitely. The Long Term Plan Respiratory Programme has also been tasked with supporting a new cohort of patients affected by Long Covid but with no additional funding.

We are concerned that resources are being diverted away from services for people with lung disease and reprioritised elsewhere. The Cardiovascular Disease and Respiratory Programme was allocated £8.4 million in NHS Long Term Plan funding for this year but over £3.5 million is being reprioritised to support people recovering from Long Covid.[[26]](#footnote-27)

The NHS Long Term Plan represented a huge step forward for people with lung disease.[[27]](#footnote-28) Significantly, the plan made lung health a priority area for the NHS for the first time. It aims to improve treatment and support for those with respiratory disease, with an ambition to transform services, treatment and outcomes to equal, or better, than international counterparts. If implemented, it would deliver real change for the 1 in 5 of us living with a lung condition in the UK but it is now being put at risk if the plan can’t be delivered because of funding uncertainties due to COVID-19.

1. Letter from NHSE and Chief Medical Officer to General Practices, 21 March 2020. [↑](#footnote-ref-2)
2. PHE, “Guidance on shielding and protecting people who are clinically extremely vulnerable from COVID-19”, available at: <https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19#who-is-clinically-extremely-vulnerable> [↑](#footnote-ref-3)
3. This statistic is an estimate and is based on datasets from across the UK: NHS Digital SPL identified over 800,000 people in England on the shielding list due to their respiratory condition (although this could possibly involve double counting of patients, as a patient can be in multiple groups): <https://digital.nhs.uk/dashboards/shielded-patient-list-open-data-set>

Public Health Scotland identified 80,000 people with respiratory disease shielding in Scotland: <https://beta.isdscotland.org/find-publications-and-data/population-health/covid-19/covid-19-statistical-report/10-june-2020> [↑](#footnote-ref-4)
4. Asthma UK and the British Lung Foundation surveyed 6345 people with lung conditions from 10 October to 19 October 2020. [↑](#footnote-ref-5)
5. Ibid [↑](#footnote-ref-6)
6. Ibid [↑](#footnote-ref-7)
7. Asthma UK and the British Lung Foundation surveyed 8495 people with lung conditions from 10 July to 15 July. [↑](#footnote-ref-8)
8. Ibid [↑](#footnote-ref-9)
9. British Lung Foundation (2016) *The battle for breath - the economic burden of lung disease*. Available from: <https://www.blf.org.uk/policy/economic-burden> [↑](#footnote-ref-10)
10. Asthma UK (2020) *The Great Asthma Divide - Annual Asthma Survey 2019*. Available from: <https://www.asthma.org.uk/support-us/campaigns/publications/survey> [↑](#footnote-ref-11)
11. Asthma UK (2019) *Paying to breathe: why unfair asthma prescription charges must be stopped*. Available from: <https://www.asthma.org.uk/support-us/campaigns/publications/prescription-charges/> [↑](#footnote-ref-12)
12. Asthma UK and the British Lung Foundation surveyed 6345 people with lung conditions from 10 October to 19 October 2020. [↑](#footnote-ref-13)
13. Philip KE, Cumella A, Farrington-Douglas J, et al. *Respiratory patient experience of measures to reduce risk of COVID-19: findings from a descriptive cross-sectional UK wide survey*. BMJ Open 2020; 10: e040951. doi: 10.1136/bmjopen-2020-040951 [↑](#footnote-ref-14)
14. Asthma UK and the British Lung Foundation surveyed 8495 people with lung conditions from 10 July to 15 July. [↑](#footnote-ref-15)
15. Ibid [↑](#footnote-ref-16)
16. Taskforce for Lung Health data analysis. Available from: <https://www.blf.org.uk/taskforce/get-in-touch/media/patients-needing-urgent-care-for-lung-conditions> [↑](#footnote-ref-17)
17. Asthma UK and the British Lung Foundation surveyed 8495 people with lung conditions from 10 July to 15 July. [↑](#footnote-ref-18)
18. Asthma UK and the British Lung Foundation surveyed 6345 people with lung conditions from 10 October to 19 October 2020. [↑](#footnote-ref-19)
19. Asthma UK and the British Lung Foundation (2020), *Recovery and reset for respiratory: restoring and improving basic care for patients with lung disease*. Available from: <https://www.asthma.org.uk/283059c7/globalassets/campaigns/publications/restarting-basic-care-final.pdf> [↑](#footnote-ref-20)
20. An ongoing survey being run by Asthma UK and the British Lung Foundation through our[post-COVID HUB](https://www.post-covid.org.uk/). Since April 2020, the survey has so far been filled in by over 3,500 people, of which nearly 3,000 had not been in hospital with COVID. [↑](#footnote-ref-21)
21. Ibid [↑](#footnote-ref-22)
22. Ibid [↑](#footnote-ref-23)
23. Ibid [↑](#footnote-ref-24)
24. Face coverings: when to wear one, exemptions, and how to make one. Available from: <https://www.gov.uk/government/publications/face-coverings-when-to-wear-one-and-how-to-make-your-own> [↑](#footnote-ref-25)
25. Asthma UK and the British Lung Foundation surveyed 8495 people with lung conditions from 10 July to 15 July. [↑](#footnote-ref-26)
26. Parliamentary question raised by Andrew Percy MP. Available from: <https://questions-statements.parliament.uk/written-questions/detail/2020-11-12/114825> [↑](#footnote-ref-27)
27. NHS England (2019), *NHS Long Term Plan*. Available from: <https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/> [↑](#footnote-ref-28)