1. Executive Summary

As the only coalition in England representing respiratory health across the entire pathway, from prevention through diagnosis, treatment, self-management and end of life care, the Taskforce for Lung Health is pleased to submit written evidence to this inquiry.

The Taskforce is a coalition of 34 members, including patients, health care professional (HCP) associations, royal colleges, the voluntary sector and industry. In 2018 we developed a five-year plan for lung health that makes 43 recommendations that we believe, if implemented, would improve outcomes for everyone living with or at risk of a lung disease.

2. How to achieve an appropriate balance between coronavirus and 'ordinary' health and care demand

Taskforce members interact with NHSE respiratory services every day. Even before the pandemic we were aware of the constraints on these services. The Taskforce's recommendations focus on improving the lives of the 10,000 people who are newly diagnosed with lung disease every week[1]. COVID-19 has highlighted shortcomings in the way NHSE operates to support people with respiratory disease and offered insights into how the system can change to better support patients and HCPs. Moreover, respiratory is a major underlying condition for people at risk of COVID-19, so addressing chronic respiratory disease can help people avoid more severe complications. Designing the post-COVID NHS landscape offers an opportunity to be aspirational and innovative, rather than restoring services to be delivered as they were previously.

3. Meeting the wave of pent-up demand for health and care services that have been delayed due to the coronavirus outbreak

i. Prevention: smoking

There is a developing evidence base that people who smoke and contract COVID-19 experience worse symptoms. 5.9 million people smoke in England. Initial findings from the largest symptom tracker app in the UK found that smoking was associated with predicted COVID-19 prevalence, and also predicted severity of the disease caused by the virus.[2]

There has been a significant rise in people attempting to quit smoking. Data from YouGov and ASH recently reported that 300,000 people in the UK may have quit smoking, with a further 550,000 making a quit attempt.[3]

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[1] British Lung Foundation (2016). The Battle for Breath – the impact of lung disease in the UK. Available here.

[2] R. Bowyer et al. 'Geo-social gradients in predicted COVID-19 prevalence and severity in Great Britain: results from 2,266,235 users of the COVID-19 Symptoms Tracker app', medRxiv 2020.

[3] Article in The Guardian, 4 May 2020. 'More than 300,000 UK smokers may have quit owing to Covid-19 fears'. Available here.

It's essential people who smoke are supported to quit to protect themselves from viral infections, including COVID-19. Additionally, smokers remain at significantly increased risk of a range of serious health problems beyond COVID-19 which require hospital admission.

Everybody who smokes should be able to access specialist support to quit, (Taskforce plan, recommendation 1a, p. 24), including vulnerable groups who are shielding. This includes getting behavioural support, nicotine replacement therapy and pharmacotherapy.

Many people no longer have access to this support due to continued reductions in funding. Remaining services are now having to adapt to a remote offer of support, but access is incredibly variable. As a priority, universal support for quitting should be made available across England, ensuring there is digital access to counselling and prescription treatments when people are shielding or socially isolating.

Additionally, all HCPs speaking to people who smoke, including people at risk of COVID-19, must be delivering Very Brief Advice (VBA) on stopping smoking, which is often the first step to becoming smoke-free (Taskforce plan, recommendation 1b, p. 27). An increase in the provision of training on VBA is therefore crucial.

ii. Diagnosis

The NHS Targeted Lung Health Checks (LHC) programme is a flagship pilot in England. People aged 55 to 74 with a smoking history are invited to a lung check with spirometry and an onsite low-dose CT scan where high cancer risk is indicated. This aims to improve early diagnosis and survival for people with lung cancer. The Taskforce is extremely supportive of this programme as a standalone project, as well as for the evidence it will provide towards the development of a national lung cancer screening programme (Taskforce plan recommendation 2e, p. 50).

NHSE's LHC programme provided funding for 14 pilot sites from 2019 for four years. When lung cancer is diagnosed at the earliest stage, more than one in three people with the disease will survive for five years or more, compared to just five in 100 people when it is diagnosed at a later stage. LHCs are essential for transforming diagnosis and survival for people with lung cancer, as well as facilitating the early diagnosis of other aggressive and chronic lung diseases such as chronic obstructive pulmonary disease (COPD) and interstitial lung diseases (ILDs).

During this pandemic, LHC sites have closed as staff are redeployed elsewhere and for the protection of patients.

It is imperative that this programme is re-started as soon as possible to utilise NHSE's funding offer and to save lives through early diagnoses. The Taskforce recognises that additional hygiene and infection control measures may need to be introduced to minimise the risk of COVID-19 spreading and these measures will reduce scanner throughput. In addition, consideration should be given to the fact that CT scanners and staff may have been redeployed from already reduced staffing levels as HCPs themselves shield or are unable to work.

iii. Pulmonary rehabilitation (PR)

PR is a programme of exercise and education classes and one of the most effective and cost-effective treatments for people with chronic lung conditions (see Taskforce plan recommendation 4b, p.77). There are historically significant issues with access to PR; only around 15% of people with COPD (MRC grade 3 and above) and 63% of people with IPF receive a referral, and there are lengthy waiting lists for programmes in parts of the country.[4] [5] The Long Term Plan committed to an expansion of PR services over the next decade. Given PR's transformative effects, it's vital this happens.

Face-to-face PR classes have stopped during the pandemic to protect patients from infection, many of whom may be shielding. When classes resume, it is likely there will be a backlog of referrals and lengthy waiting lists and consideration must be given to the need for continued social distancing.

While some PR providers are exploring digital alternatives to face-to-face classes, this service is not currently available to all respiratory patients either because the provider does not offer an alternative or because people are digitally excluded. For those shielding or considered vulnerable to COVID-19, remote consultations and digital PR programmes should be offered and accessible to all who would clinically benefit. Continued and increased access to self-management interventions such as PR are vital to help people with lung conditions stay well whilst at home and for resilience to later 'waves' of COVID-19.

4. Meeting extra demand for mental health services as a result of the societal and economic impacts of lockdown

i. Mental health and respiratory

We know that mental health problems go hand-in-hand with the symptoms and effects of lung disease (breathlessness, lack of mobility, isolation) leading some people to experience anxiety and depression. For this reason, we recommend that respiratory guidelines should involve positive interventions for people with mental health problems (see Taskforce plan recommendation 3g, p. 67).

Now, we are especially keen to ensure that people with an existing lung health condition can access appropriate and timely mental health support. Many primary care professionals are saying that an increasing number of their appointments are for mental health issues.

Given we are in the infancy of understanding the impact of shielding on people at risk, including those with lung disease, and we have yet to understand the medium-term impact of having COVID-19 on people's mental health, it's important for data to be collected on the interplay.

ii. End of life

The need to have rapid and remote consultations with patients that around end of life care has highlighted some HCPs lack of confidence. These are deeply personal and difficult

[4] Royal College of Physicians (2016). Pulmonary Rehabilitation: Steps to breathe better.
[5] British Thoracic Society (2019). ILD Registry Annual Report 2019.

conversations that need tailored training so there is shared decision-making. HCPs have reported to the Taskforce that they find this extremely challenging. Primary care professionals in particular have told us they lack the skills and confidence to have these conversations with their patients. These conversations are vital so patients understand their choices and feel their HCPs have understood their needs.

Given that COVID-19 has highlighted this need, it's pertinent to reinforce our recommendation that everyone with long-term respiratory disease should be involved in shared decision-making around end of life (Taskforce plan, recommendation 5a, p. 94).

We need a comprehensive rollout of training to HCPs to support patients at the end of their lives by offering basic end of life care advice. This includes them being aware of, and offering, a range of therapies to help mitigate breathlessness, pain, depression and anxiety and for HCPs to have these conversations in a sensitive and effective way (Taskforce plan, recommendations 5c & 5e, p. 97 & 100).

5. Meeting the needs of rapidly discharged hospital patients with a higher level of complexity

i. Support plans

People living with a lung disease need clear and accessible information and support on managing their condition. For this reason, the Taskforce recommends that every person with lung disease has a personalised care and support plan. Patients, families and carers should have access to relevant information about their condition, treatment and management (Taskforce plan, recommendation 4a, p. 72). Given the complexities of recovery from COVID-19, and the fact that many patients have multiple long term-conditions, the need for this is only heightened.

ii. Post-COVID

Early studies show that some people recovering from a severe case of COVID-19 can have ongoing breathing difficulties. While it's too soon to say what kind of lung damage is occurring or how many people will be affected, it's vital to ensure these people receive the necessary support. It's likely this will involve rehabilitation and there will be significant demand for services that are already under pressure. Patients must have access to an appropriate rehabilitation programme, whether they are in ITU, have been discharged or managed in the community.

Several Taskforce members have contributed to the creation of a new Post-COVID Hub and helpline to support people experiencing post-COVID breathing difficulties. This provides information on research opportunities for academics and the latest care guidelines for HCPs.

6. Providing healthcare to vulnerable groups who are shielding

The Taskforce recognises there are many patients who may still need to shield once the current lockdown eases. People with existing progressive lung disease, such as COPD and ILD, have had much of their regular care and consultation put on hold. Anecdotally, we have

heard from our members that people with an already-limited life expectancy have had their much-valued appointments cancelled or delayed for many months. This is despite the fact their progressive disease continues to advance.

Consideration of these people, including treatment, advice, surgery, and medications, must be part of the lockdown exit strategy. For example, the needs of patients requiring medications reviews, personal action plans, medicines optimisation advice, surgical procedures, oxygen therapy and PR, must all be met in any post-COVID landscape.

i. Medication reviews

The COVID-19 pandemic has meant the introduction of Structured Medications Reviews (SMRs) as part of the PCN contract have been paused until October. This has coincided with advice on social distancing, when existing respiratory patients are unlikely to access community pharmacies in a way they may have done previously, for advice on their medications, including advice on inhaler technique.

Consideration must be given to ensure that once the pandemic is over, patients can access via alternative means the advice and help they need and which, pre-COVID, were able to access from community pharmacies as well as general practice. This may include virtual inhaler technique reviews; we would urge NHSE to engage with relevant stakeholders to consider viable models for these.

Consideration must be given to administering flu and pneumonia vaccinations to those who are shielding.

7. How to ensure that positive changes that have taken place in health and social care as a result of the pandemic are not lost as services normalise.

i. Treatment

The Taskforce is aware that home spirometry testing is being trialled for patients with cystic fibrosis. We would like to see this service evaluated, and continued or expanded to other patient groups, if appropriate.

ii. Alternatives to face-to-face visits

The pandemic offers a unique chance to evaluate digital interventions at scale. We would like to see thorough evaluation of the different ways of providing medications reviews and inhaler technique checks, so that any practices which prove to be as effective as face-to-face *and* which are more convenient for patients, can be considered for more routine adoption in the future.

iii. PR and digital healthcare

There has long been scope to make better use of digital in respiratory care, and we hope there will be valuable learning of what has and has not worked during this time as the NHS has rapidly pivoted to digital-first services. A digital-first approach is essential in protecting patients and staff from avoidable exposure to infection, facilitating rapid access to advice and information, and supporting system stability by enabling remote working. We need to ensure that in the significant roll-out and uptake of online health consultations, people with lung disease can continue to access safe, accurate and timely care from their HCP.

It is important that learning and appetite for innovation is captured by the NHS and embedded in the longer term. We will also need to quantify the negative effects, ensuring that we know how best to balance digital with face to face care in the future and that no one is left behind because of a lack of digital skills or access.

For example, some PR services have made use of video-conferencing or interactive online PR platforms to deliver classes. We need to assess and understand the best model for delivering digital PR as the current evidence base is limited. There would also need to be investment in new equipment, training and staff in order to adequately meet increased need and demand.

iv. Flu

The Taskforce report calls for an increased rate of flu vaccination among the clinical at-risk groups and front-line NHS and social care staff who have contact with patients (Taskforce plan, recommendation 1h, p. 35).

Maintaining the national immunisation programme during the pandemic is crucial to provide protection to vulnerable groups and reduce preventable pressure on the NHS during any future 'peaks.' As highlighted by NHSE, the JCVI and RCGP, this will be particularly important for other vaccine-preventable respiratory viruses such as flu and pneumonia. NHS services have been asked to deliver as much preventative work, including vaccination, as can be provided safely, and to expect an expanded winter flu vaccination campaign this year. This should involve consideration of how routine vaccinations such as flu and pneumococcal can be provided safely and the risk of COVID-19 infection reduced, for example through use of PPE.

The flu 'at risk' group was originally used to determine the government's shielding criteria. Uptake of the flu vaccine among the clinical at-risk group is low; just 48% received the vaccine last year. Boosting flu vaccine uptake among this group will help keep some of the most vulnerable people out of hospital.

We also need to see near-universal uptake of the flu vaccine among health and social care workers with direct patient contact. 70.3% of frontline NHS staff received the jab in 2018-19, with wide variation between trusts. No national data is currently collected on social care staff vaccine uptake – a system for data collection must be urgently developed.

9. Other

i. Learnings around social distancing

We are aware that in due course, social distancing may be found an effective measure for slowing the spread of winter respiratory illness such as flu, as well as COVID-19. It would be useful to consider how the learnings from this impact the flu season for winter 2020/21 and beyond. In future, NHSE may want to encourage certain patient cohorts to social distance to reduce winter hospital admissions, and to lower the need for existing respiratory patients to visit hospitals for exacerbations of pre-existing conditions.

ii. Data

Current data sets around COVID-19 are imperfect. To ensure we can best support future people with lung disease, who may have had COVID-19, NHSE and the government needs to increase the quantity and quality of existing data sets. They must ensure data is:

- Accurate and captures all settings including care homes and community.
- There should be a push for retrospective testing to better understand how many people have been affected.
- Demographic data should be captured throughout to enable future analysis.
- Patient health data including preceding health status, smoking status, underlying/preceding conditions, pathway through services, recovery status, and post-Covid-19 health status including mid to long-term effects.

New data relevant to COVID-19 that is needed includes:

- What treatments have been provided and the efficacy of these.
- Accurate coding in healthcare records on COVID-19 – whether it is formally tested, self-diagnosed, or via the antibody test. This is essential to diagnose and treat future respiratory diseases as they may emerge in people who've had COVID-19.
- Monitor the effectiveness of digital healthcare in providing care, to include patient reported outcomes and QoL measures.
- The number of patients with COVID-19 with a shared decision-making plan.
- The relationship and combined impact of COVID-19 and flu.
- Follow-up data on the COVID-19 recovery cohort.

More broadly, we need the urgent delivery of the agreed respiratory Long Term Plan metrics, particularly with regards to diagnosis and primary care management.

It will not be possible for NHSE to effectively and accurately provide shielding advice in advance of a potential future second wave without knowing who is vulnerable.

11. Close

The Taskforce is happy to assist the committee further on these issues. For more information contact Danielle Roe, Policy and Projects Officer for the Taskforce, on droe@auk-blf.org.uk