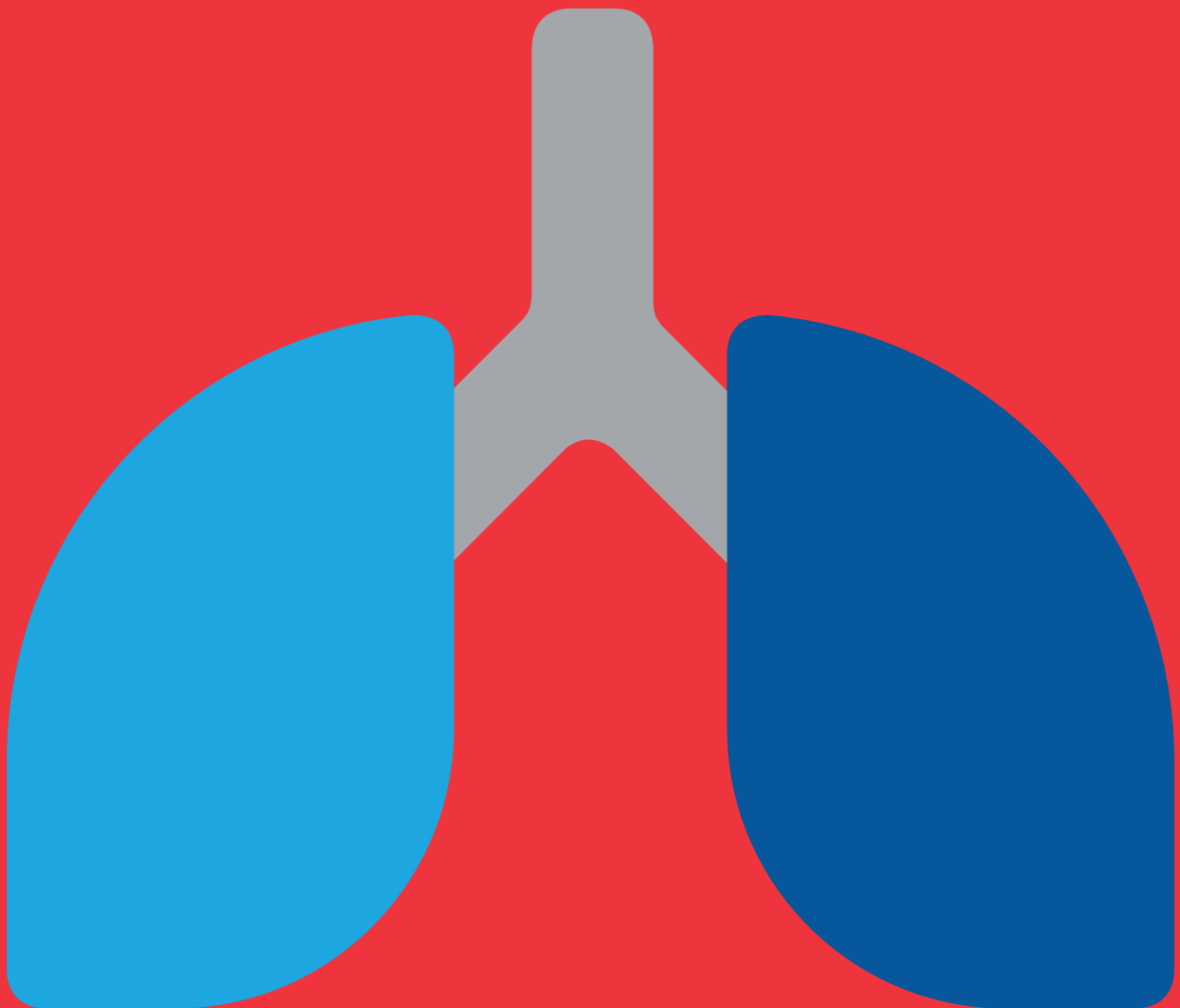


A National Five Year Plan for Lung Health

A five year plan to create a society where everyone can live with healthy lungs for as long as possible and have the best chance of living well, or recovering, when lung disease develops.



Taskforce for Lung Health

This five year plan has been prepared by the Taskforce for Lung Health, chaired by Dr Alison Cook and Dr Penny Woods.

The Taskforce is independent of government. Its membership includes 29 organisations, representing people living with lung disease, health care professionals, the voluntary sector and professional associations. These are:

Action for Pulmonary Fibrosis: Steve Jones

The Association of the British Pharmaceutical Industry: Su Jones

Association of Chartered Physiotherapists in Respiratory Care: Ian Culligan

Association for Respiratory Technology & Physiology: Dr Karl Sylvester

Asthma UK: Krishnah Poinasamy

British Geriatrics Society: Dr Chris Dyer

British Lung Foundation: Sarah MacFadyen

British Society of Thoracic Imaging: Dr Anand Devaraj

British Thoracic Society: Sheila Edwards

Chartered Society of Physiotherapy: Rachel Newton

Cystic Fibrosis Trust: Anna Evans

Health and Safety Executive: Sarah Mallagh

Interstitial Lung Disease Interdisciplinary Network: Sarah Agnew

NHS RightCare: Vittoria Polito

Patient representative: Jay Dowle

Patient representative: John Conway

Patient representative: Surayya Khan

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Respiratory Futures: Sheila Edwards

Roy Castle Lung Cancer Foundation: Mike Grundy

Royal College of Anaesthetists: Dr Tom Pierce

Royal College of General Practitioners: Dr Steve Holmes

Royal College of Nursing and Association of Respiratory Nurse Specialists: Wendy Preston

Royal College of Nursing: Eleanor Sherwen

Royal College of Paediatrics and Child Health: Emily Arkell

Royal College of Physicians: Viktoria McMillan

Royal College of Radiologists: Dr Sam Hare

Royal Pharmaceutical Society: Heidi Wright

Society of Cardiothoracic Surgery in Great Britain and Ireland, on behalf of the Royal College of Surgeons: Mr Babu Naidu

The Taskforce project was also supported by the Industries Forum, a group of 11 companies which submitted evidence in support of this plan. The Industries Forum was represented on the Taskforce by the Association of the British Pharmaceutical Industry. The members of the forum are listed below:

AbbVie, The Association of the British Pharmaceutical Industry, AstraZeneca, Boehringer Ingelheim, Chiesi Limited, GSK, Novartis UK, Pfizer, Roche, Sanofi, Seqirus (non-ABPI member)

The ABPI facilitated the individual companies that were part of the Industries Forum to provide evidence to the Taskforce evidence gathering process.

Some members of the Industries Forum coordinated with the British Lung Foundation to provide financial support to the Taskforce. These companies are acknowledged at the end of the report. Other than this acknowledgement, no distinction was made between input from companies which contributed financially and those which did not.

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Forewords

Professor Sir Michael Marmot

Director of Institute of Health Equity UCL and President of the British Lung Foundation

Look at a paper at random on international comparisons in mortality in Europe – I just looked at two – and you will find ischaemic heart disease, cerebrovascular disease, cancer(s) and ‘other’ or ‘non-cancer, non CVD’. It is entirely appropriate that ischaemic heart disease, cerebrovascular disease and cancer(s) should be there. But something huge is missing: lung diseases. They are just ‘other’.

The World Health Organisation (WHO) reports that in 2015 there were 56 million deaths globally. The two biggest killers were indeed ischaemic heart disease and stroke, accounting for about 15 million deaths annually. The next three in the top ten, though, were diseases of the lungs, with lower respiratory infections, influenza and pneumonia accounting for 3.2 million deaths; chronic obstructive pulmonary disease, 3.2 million deaths; and cancer of the trachea, bronchus and lung, 1.6 million.

Paying attention to prevention and treatment must be a global priority, but in the UK too, where one in five people live with lung disease, we must do more to understand the causes, prevention, treatment and management of people with lung disease, and put in place appropriate actions.

Inequalities have long been a striking feature of lung diseases in the UK. Since Victorian times we have spoken of Dickensian conditions. People living and working in conditions of foul air and infections, those relatively poor, had an appalling burden of lung disease. As conditions have improved

markedly, and the population become healthier, there is still a clear social gradient – the more deprived the area in which people live, the higher the mortality and morbidity from lung diseases. Of the many indignities associated with being poor, or relatively so, having increased risk of chronic obstructive pulmonary disease or dying of lung cancer or pneumonia are among the worst.

The tragedy of it is that we know quite a bit about what to do to prevent this needless suffering. This report highlights causes of lung disease – smoking, air pollution, occupational exposures – along with lack of access to treatment and care. I talk of ‘the causes of the causes’. Smoking and air pollution are causes of lung disease. We need to pay attention to why people lower in the hierarchy are more exposed to these causes. Simply blaming the poor is not just useless in achieving change, it does not fit with the evidence.

There is much in this report that has the potential not only to improve health for the whole population, but to reduce inequalities in health. The specific recommendations are very welcome. They should be acted on along with broader actions to reduce social and economic inequalities in society.



Dr Penny Woods

Chair of the Taskforce

Lung disease is a blight on modern society and people living with lung disease in England get a raw deal. Compared to other countries we do badly in diagnosis and in treatment and could do better in preventing lung disease in the first place. The Taskforce for Lung Health sets out in this report key policy and practice changes which, if taken together, would create the step change in outcomes that we so desperately need for people living with lung disease.

For the first time, the respiratory professional, patient and academic communities are working together as the Taskforce for Lung Health to look at how we can make improvements to death rates from lung disease, which have been static for the past decade. The collaboration of professional bodies, people with lung disease, royal colleges and respiratory charities to recommend changes across the whole patient pathway from prevention to end of life is truly momentous.

We are already seeing the benefits of this united approach. Respiratory, along with cardiovascular, disease is for the first time an official priority in NHS England's Long Term Plan. This recognition is long overdue, and extremely welcome. NHS England is planning to focus on preventing lung disease, early and accurate diagnosis, medicines optimisation and pulmonary rehabilitation. But there is a lot more to do beyond these specific areas, if we are to see lasting and comprehensive improvement and a real difference to people living with lung disease. The Taskforce stands ready

to work with the government and policy makers across the whole health and care system to achieve sustainable and meaningful improvements.

Measuring this change from the perspective of people with lung disease will be crucial. People diagnosed with cancer already have this feedback mechanism in the National Cancer Patient Experience Survey. We now need an equivalent national survey to monitor progress from the perspective of people diagnosed with lung disease. Investment is also needed in public awareness-raising. Generally, lung disease is poorly understood and people with lung conditions are subject to prejudice and stigma; this ignorance must end if we are to make true progress in how society regards lung disease, its causes and effects. Awareness-raising efforts are also crucial if we are to convince everyone to look after their lungs as best they can, and for everyone to know the warning signs to look out for, so we can diagnose and treat lung disease early.

The Taskforce is committed to working tirelessly to bring to life the recommendations in the report. I am, now more than ever before, confident that we can start to deal a better hand to people living with lung disease.



Executive summary

One in five people live with lung disease. Respiratory conditions are responsible for a major part of the gap in life expectancy between the poorest and wealthiest. Despite this, there is no comprehensive national plan in place for lung health.

The Taskforce for Lung Health was convened in 2018 to develop a five year plan to improve lung health in England. We are a unique collaboration between patient representatives, health care professionals and other experts with a shared vision for lung health. While England is our primary focus because health and social care is run differently in each UK nation, our vision to improve lung health is for the whole of the United Kingdom. Progress has already been made in Wales and Scotland is poised to deliver its own plan.

The Taskforce requested evidence on real-world examples of policy or practice that would improve outcomes for people with a lung condition.

This report sets out the Taskforce's recommendations for change, based on the evidence we received. We outline the data we need to measure progress and set specific targets for our recommendations. In some cases we are looking for results year by year, and in others we are looking for results after five years.

Prevention is a key priority. The Taskforce has identified steps to reduce the risk of developing lung disease, supporting people to make healthier choices and helping to protect their lungs. This must include children and young people.

We make recommendations to plan and fund effective, high-quality stop smoking services and to train all health care professionals in very brief advice on smoking cessation. The Taskforce also calls for Clean Air Zones in cities and towns, including a national system of air pollution alerts with health advice. There are recommendations to reduce the risk of lung disease caused by work and to promote the benefits of annual flu jabs more widely to help protect the most vulnerable by reducing the risk of infection.

Implementation of our recommendations would reduce the number of people who smoke, improve the quality of the air we breathe in our communities, and make our workplaces safer.

// Early and accurate diagnosis is critical to survival rates

Early and accurate diagnosis is critical to survival rates for people with lung disease. The Taskforce makes recommendations to improve early detection by creating clear pathways with services for timely, accurate and complete diagnosis for all people with breathlessness and other respiratory symptoms. There are also recommendations for an enhanced role for community pharmacists and another for a single, consistent guideline for the diagnosis and

management of asthma. Implementation of a national lung cancer screening programme is recommended, together with targeted case-finding for people who have symptoms suggestive of chronic obstructive pulmonary disease (COPD) in general practice.

Our recommendations will significantly increase opportunities for earlier diagnosis of lung disease. Treatment will begin earlier and be more effective, allowing more people to live well and work for longer, and do the things that they want to do.

// Treatment must be available to all patients when they need it

Action is also needed to improve outcomes by making sure that treatment and therapies are available to all patients when they need it. The Taskforce makes recommendations to improve access to lung transplant and to expand access to lung volume reduction surgery. It also recommends wider use of enhanced recovery after surgery (ERAS), which uses non-pharmacological treatments like exercise and diet to help with recovery after surgery.

Our recommendations for medication cover improvements in the use of inhalers to treat asthma and COPD. The Taskforce also asks the government and the pharmaceutical

industry to work together to improve access to antifibrotic drugs for idiopathic pulmonary fibrosis (IPF), medicines for cystic fibrosis and monoclonal antibody treatments for severe asthma.

There should be full implementation of oxygen therapy guidelines and quality standards to improve use of home and ambulatory oxygen. Respiratory guidelines should include positive interventions for patients with mental health problems.

To help people live well with lung disease, there is a Taskforce recommendation for all people with lung disease to have a personalised care and support plan. Patients, families and carers should have access to relevant information about their condition, treatment and management. Access to pulmonary rehabilitation should be improved and the use of non-pharmacological treatments for breathlessness and cough should be expanded. Support groups for people with lung disease, their families and their informal carers should be promoted and made more accessible. The Taskforce also recommends expansion of the delivery of NHS Medicines Use Review and NHS New Medicine Services in pharmacies.

The Taskforce wants more people to have a greater say over where they receive care at the end of their lives. It recommends that every person with a lung disease and their carers should have access to a shared decision-making programme, with support to stay at home if appropriate. Health care professionals should be aware of the range of therapies that can help with and

mitigate breathlessness, pain, depression and anxiety at the end of life. All health care professionals should be able to offer basic end of life care advice.

// We need a respiratory workforce fit for the future

Implementing the Taskforce recommendations requires a respiratory workforce fit for the future. This includes a wide range of health care professionals such as nurses, physiotherapists and GPs. The Taskforce makes recommendations to support staff who can work together to deliver excellent care for patients with a lung condition. It calls on NHS England to take a leading role, working with relevant professional bodies. While this report makes recommendations for different professions, there is consensus that multi-disciplinary teams are the best way forward.

The Taskforce welcomes NHS England's decision to include respiratory disease as a priority clinical area in the new NHS Long Term Plan now being developed in partnership with NHS Improvement.

This is an important step towards delivering the high-quality care to which people with lung disease are entitled. We look forward to working with NHS England and NHS Improvement on the implementation of our recommendations, for the benefit of patients and their families.



Summary of recommendations

Keeping lungs healthy

Recommendation 1a: Plan and fund effective, high-quality stop smoking services which are accessible to everyone who wants to quit

Recommendation 1b: All health care professionals to be trained in offering very brief advice on smoking cessation

Recommendation 1c: Introduce category D Clean Air Zones in the most polluted towns and cities across England

Recommendation 1d: Place new restrictions on particulate matter (PM) emissions from all sources

Recommendation 1e: Government to introduce a national system of air pollution alerts with health advice

Recommendation 1f: Improve the awareness of and compliance with the Control of Substances Hazardous to Health Regulations 2002 (COSHH) to prevent and control workplace exposures

Recommendation 1g: Embed understanding of occupational lung disease in undergraduate and postgraduate health care professional training and ensure continuing professional development programmes in relevant clinical groups maintain knowledge in this area

Recommendation 1h: Increase rate of flu vaccination among the clinical at-risk groups and front-line NHS and social care staff who have contact with patients

Identifying lung disease early

Recommendation 2a: Create a clear patient pathway with services for timely, accurate and complete diagnosis for all people with breathlessness and other respiratory symptoms

Recommendation 2b: Develop a formal referral system to enable community pharmacists to refer people directly to general practice or other appropriate organisations

Recommendation 2c: Develop a single consistent guideline for diagnosis and management of asthma, including referral to tertiary services as appropriate for difficult or suspected severe asthma and ensure appropriate resources for implementation

Recommendation 2d: Introduce targeted case-finding for people who have symptoms suggestive of chronic obstructive pulmonary disease (COPD) in general practice with follow-up care and services

Recommendation 2e: Implement a comprehensive national lung cancer screening programme, targeting those at high risk of developing lung cancer, and offering them low dose CT screening

Better care for all

Recommendation 3a: Establish clear best practice in assessment, referral and regular monitoring of all people who would benefit from a lung transplant

Recommendation 3b: Establish clear best practice in assessment, referral and regular monitoring of people with advanced chronic obstructive pulmonary disease (COPD) and advanced breathlessness who would benefit from a lung volume reduction procedure

Recommendation 3c: All surgery units to employ enhanced recovery after surgery (ERAS) guidelines with a specific focus on lung health

Recommendation 3d: Improve inhaled therapy, by developing a clear pathway for accurate prescribing and adherence, and promoting new technology such as smart inhalers

Recommendation 3e: The government and pharmaceutical industry should work together to improve access to antifibrotic drugs for idiopathic pulmonary fibrosis (IPF), cystic fibrosis transmembrane conductance regulator (CFTR) modulators for cystic fibrosis and monoclonal antibody treatments for severe asthma

Recommendation 3f: Fully implement British Thoracic Society (BTS) home oxygen therapy guidelines to improve use of home and ambulatory oxygen. Fully implement

the National Institute for Health and Care Excellence (NICE) quality standard on idiopathic pulmonary fibrosis (IPF) to ensure patients have access to beneficial home and ambulatory oxygen therapy

Recommendation 3g: Respiratory guidelines should involve positive interventions for people with mental health problems

Living with a lung disease

Recommendation 4a: Every person with lung disease to have a personalised care and support plan. Patients, families and carers should have access to relevant information about their condition, treatment and management

Recommendation 4b: Improve access to pulmonary rehabilitation so that every person with an MRC breathlessness score of grade 2 and above is identified, referred to, and has the opportunity to complete, a programme

Recommendation 4c: Expand the use of non-pharmacological treatments for breathlessness and cough

Recommendation 4d: Promote and signpost people living with lung disease, families and carers to support groups which are run in joint leadership between people affected by lung disease and health care professionals

Recommendation 4e: Expand the delivery of NHS Medicines Use Review and NHS New Medicine Services in pharmacies and remove the cap on the number of these they can deliver

The right care in the last year of life

Recommendation 5a: Every person with lung disease and their carer(s) should have access to a shared decision-making programme where they can identify areas where they need additional support

Recommendation 5b: People with lung disease should be supported to stay at home where appropriate

Recommendation 5c: Health care professionals should be aware of the range of therapies that can help with and mitigate breathlessness, pain, depression and anxiety at the end of life

Recommendation 5d: Generalist and specialist respiratory and end of life services should work together to deliver end of life care

Recommendation 5e: All health care professionals should be able to offer basic end of life care advice

A workforce for the future

Recommendation 6a: NHS England to provide a clear vision of required health care professionals for a developed workforce for quality provision of respiratory care to Health Education England by 2020

Recommendation 6b: Expand the NHS England drive to ensure that as many health care professionals as possible work at the highest end of their remit, for example advanced clinical practitioners and assistant practitioners

Recommendation 6c: NHS England and Health Education England to refresh GP strategy with a focus on retention as well as recruitment

Recommendation 6d: Create an additional 100 respiratory speciality training posts over five years (20 per year)

Recommendation 6e: NHS England and the government must focus on recruitment and retention of nurses, including reviewing the funding mechanisms for training and continuing professional development programmes

Recommendation 6f: The Royal College of Radiologists, supported by the British Society for Thoracic Imaging, to introduce national standards for speed of reporting

Recommendation 6g: Invest in sufficient workforce and equipment to ensure all departments are reporting at the speed of the fastest

Recommendation 6h: Create regional thoracic imaging networks to share expertise between hospitals

Recommendation 6i: 500 additional training places to be made available by Health Education England, and delivered by the National School for Healthcare Science, to fill the current gap in the respiratory and sleep physiology/health care scientist workforce, with commissioners and providers being aware that business

cases for new respiratory consultants should include the need for greater respiratory and sleep physiology/health care science workforce capacity to support them

Recommendation 6j: Continue to increase physiotherapy training places to meet target of at least 600 additional physiotherapists over five years

Recommendation 6k: Where appropriate, commission joint community rehabilitation services (for instance linking with cardiac rehabilitation) to support patients with co-morbidities while making best use of the workforce

Recommendation 6l: Provide more training places for pharmacists in GP practices

Recommendation 6m: Include consultant pharmacist posts in strategic workforce plans



Case for
change

One in five people live with lung disease and countless more are affected caring for loved ones.¹ This costs the UK more than £11 billion a year, including the impact on the NHS and the wider economy through working days lost.²

Respiratory conditions are responsible for a major part of the gap in life expectancy between the poorest and wealthiest in the UK. People are twice as likely to develop lung cancer or chronic obstructive pulmonary disease (COPD, or chronic bronchitis and emphysema) if they are in the most deprived 10% of the population, compared to the richest.³

Despite this, there has never been a comprehensive national plan in place for lung health in England. It has, until now, not been considered a priority. People with lung disease face the additional disadvantage of prejudice and stigma, being blamed for their own condition because of perceived lifestyle choices.⁴ Public awareness of what lung disease is and how to prevent it is poor.

We have a dedicated workforce who are committed to giving patients the best care and support. Yet this historic lack of national focus is why there has been no improvement in mortality rates for people with lung disease for more than 10 years.⁵ While other countries have made significant progress, the UK has been left behind, and so have people with lung disease and their families. The government has now included respiratory disease as one of four clinical priority areas in the new Long Term Plan for the NHS in England. This is an important step forward. But much more needs to be done.

Across England access to services, treatment and support is fragmented. Opportunities

- 🕒 **One in five people have been diagnosed with lung disease**
- 🕒 **Lung disease costs the UK more than £11 billion a year**
- 🕒 **Outcomes have not improved in more than 10 years**
- 🕒 **There has been no comprehensive national plan for lung disease**
- 🕒 **Research into lung disease is underfunded**

for diagnosis are missed. Treatment and care have changed but with little improvement this century. Innovation has been patchy and there has been limited uptake of new technologies.

Research funding is not proportionate to the scale of lung disease. The most recent analysis of spending by government agencies, industry and charities shows that just £31 million was invested in respiratory research in 2014, accounting for just 1.64% of overall research spend.⁶ Infectious diseases, for instance, are responsible for about half the burden on society that respiratory conditions are, but received about seven times more research funding.

The time to act is now as new evidence of threats to lung health emerge, such as poor air quality and work-related lung disease. Although smoking is in decline, numbers of new cases of lung disease continue to rise.

The Taskforce for Lung Health was convened to bring together representatives of people living with lung disease and leading experts in a unique collaboration.

Together we have developed a five year plan to improve the nation's lung health.

This is our call for action to decision makers to take steps now, without delay, to implement the Taskforce's recommendations.

It is the right thing to do. It is the fair thing to do because it will create a society where everyone can live and work with healthy lungs for as long as possible and have a better chance to live well and work when lung disease is diagnosed.



// One in five people has a history of lung disease

As an interstitial lung disease (ILD) specialist nurse at Liverpool's Aintree University Hospital, Sarah Agnew cares for acutely ill patients from some of the poorest communities who are then let down by a system that puts other diseases first.

"Lung conditions such as COPD or ILD affect so many people and their families," says Sarah. "One in five people has a history of lung disease, but it is overshadowed by cancer and stroke and receives a smaller share of health

care resources but has similar – and in some cases worse – outcomes regarding disability and life expectancy. It affects the poorest people disproportionately who are then unable to access the level of care and support they need."

The stigma of lung disease persists, with many people still believing that it is largely self-inflicted. "The public know less about respiratory diseases and that influences how resources are allocated."



// There can be a stigma surrounding lung conditions

A diagnosis of lung disease has a devastating emotional impact, as well as a physical one. People with lung disease can feel alone and isolated from the community as they struggle with their condition.

John Conway was diagnosed with ILD when he was 51. Says John, now 54: "In three years I have gone from being fit, healthy and very active, to struggling to breathe when walking up a flight of stairs or up a slight incline."

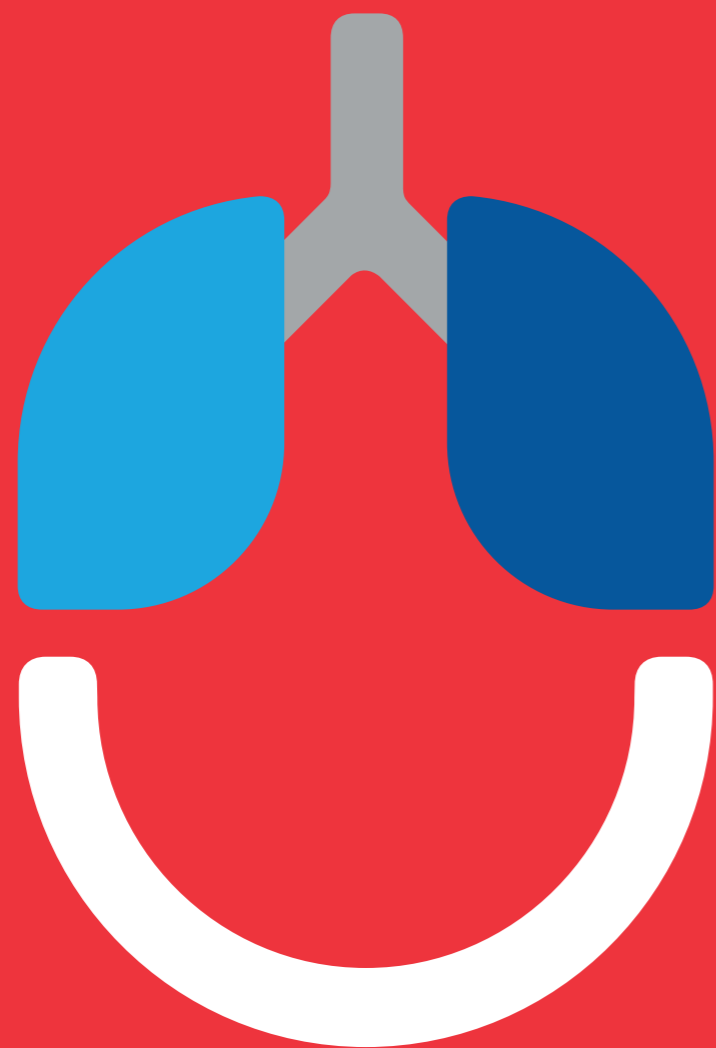
As his condition has progressed, John has had other challenges to overcome: "There can be a stigma surrounding lung conditions. As my condition is hidden, people can't see how unwell I really am. People may assume it is something that has developed because of the way I live, and that I am or was a smoker. But until I became ill I was the ideal blueprint for a healthy life: never smoked, had a healthy diet and exercised regularly."

John, who lives in south-west London, had to reduce his working hours because of his condition and now works part-time for a social enterprise based in east London. "For me, it is very important to continue professionally for as long as I can and to continue to contribute to society. But it is a challenge to get ready for the commute to work, especially if there are a lot of stairs on the route."

He has helped to set up an ILD support group at St George's Hospital in Tooting. "Support groups are vital," John says. "You can learn so much about managing your condition and staying as well as possible. But they are also an opportunity to be with other people who understand what it is like to live with a chronic lung disease."

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Chapter 1:
**Keeping
lungs healthy**

We are all at risk of lung disease, but there are steps we can take to protect ourselves and our loved ones and to reduce the risk. It is important to give people the information and support they need to make healthier choices. But we also need to take action to ensure that the air we breathe in our communities is clean and safe and that our places of work provide the protection our lungs need. Keeping our lungs healthy is everybody's responsibility.

Smoking

The number of people who smoke is at an all-time low. But 6.1 million adults still smoke.¹ And people living in the greatest areas of deprivation remain over four times as likely to smoke as those in the least deprived areas.² We must do more to help people quit their dependence on tobacco throughout the health care system and more to stop people from taking up smoking in the first place, particularly children and young people. Tobacco dependency must be recognised as a potentially fatal chronic relapsing disease.

Stopping smoking is often the best available treatment for people with lung diseases who smoke.³ It is essential that support to quit smoking is ingrained within patient pathways.

Stop smoking services play a vital role in supporting people to quit but they are currently in decline. They provide the most successful way to stop. Smokers are approximately four times more likely to quit smoking successfully with support from stop smoking services.⁴

Recommendation 1a:

Plan and fund effective, high-quality stop smoking services which are accessible to everyone who wants to quit

Local authorities and NHS trusts should work with clinical commissioning groups to ensure that all smokers have access to the treatment and behavioural support they need to quit.

The government must reverse the decline in funding for local stop smoking services. Services across England are being cut at a time when they must be maintained in order to keep up momentum on falling smoking rates. Half of local authorities cut their budgets for stop smoking services in 2017.⁵ Four in 10 local authorities do not provide support for smokers in line with the National Institute for Health and Care Excellence (NICE) guidelines, including 17% which have replaced specialist services with an integrated lifestyle service.⁶ NICE recommends stop smoking services are made available for everyone who smokes.⁷

Commissioners should have clear plans to tackle local inequalities in smoking, addressing the needs of disadvantaged smokers who are likely to need particular attention to give them the best chance of quitting. Services need to involve specialist support for people at highest risk, including people with mental health problems, pregnant women, young people and people already living with a lung disease.

Preventative measures must reflect the long-term disabling impact of chronic lung disease caused or aggravated by tobacco dependence. For instance, people who smoke are nearly five times more likely to get flu than non-smokers.⁸

Measures of success:

Increase in the number of people setting a quit date through an NHS stop smoking service from 274,021 in 2017–18, as monitored by NHS Digital.

Increase in the number of people who have stopped smoking using an NHS stop smoking service, in both quitters who are self-reported and those who are carbon monoxide validated, as monitored by NHS Digital.

Decrease in the total adult smoking rate from 14.9% to 12% or less by 2022, in line with the Tobacco Control Plan for England.

All local authority areas to commission specialist stop smoking services open to all smokers, and all NHS trusts to run in-house stop smoking services for all patients, in line with NICE guidelines.

Data need: Public Health England to start monitoring provision of local authority stop smoking services and NHS trust stop smoking services within one year.



“Smokers should be made aware of the debilitating effects of COPD, as well as the life-shortening effects of smoking. If I had known the impact that COPD would have on my life in terms of severely limiting me in the everyday things I want to do, and even those I need to do, I would probably have stopped smoking long before I did. Had I been told at the age of 40 that I already had the lung age of a 60-year-old it would have been a real wake-up call. These sorts of messages can really hammer home the impact of smoking.”

Jay Dowle, who lives with COPD



Chris Dodd, 46, lives in Swindon. He has lived with asthma since childhood and was diagnosed with chronic obstructive pulmonary disease (COPD) in 2011. He began smoking in his teens and continued until 2014. He typically smoked a packet of 20 a day, more if he was enjoying a pint at the pub. "Most of the time I was reasonably healthy, despite my asthma," says Chris. "I knew that smoking wasn't good for me but so long as it didn't appear to be affecting my daily life I thought I could continue."

But his lung health began to deteriorate in 2009 when he was treated for mycobacterium xenopi, a pulmonary infection. In 2011 he was diagnosed with COPD. This was the catalyst for his decision to quit smoking. After a number of false starts he succeeded in kicking the habit, supported by a stop smoking nurse at his local GP surgery. "It made

a huge difference to have her support and experience," says Chris. He began with e-cigarettes and nicotine lozenges, and gradually cut down the number of cigarettes. "The lozenges made me feel quite sick, which was good in a way because I wanted to stop using them as quickly as possible," says Chris. He stopped smoking altogether within nine months.

Chris says he doesn't miss smoking, and has enjoyed a number of benefits, including long walks with his dog every day. Although other health issues have been a concern, Chris feels he has been better placed to deal with them because he no longer smokes. "I would encourage anyone to stop smoking, particularly if you have a lung health problem. It is not easy, but using a stop smoking service makes all the difference."

Recommendation 1b:

All health care professionals to be trained in offering very brief advice on smoking cessation

Every contact with a patient is an opportunity to provide advice on quitting. Very brief advice can be effective in encouraging smokers to quit. Yet half of all frontline health care staff are not offered regular training in how to support people to quit.⁹

Smokers may need several tries to quit smoking successfully, so it is important to keep giving advice at every opportunity. Very brief advice takes as little as 30 seconds and can be given by anyone, but is most powerful when it comes from a health care professional.

Asking someone about their smoking and being able to refer a smoker to a specialist stop smoking service is recommended for all health care professionals who meet smokers through their work.¹⁰ A recent audit of 146 hospitals found nearly three out of four smokers were

not asked if they would like to quit smoking, and only one in 13 was referred to a stop smoking service.¹¹

All commissioners should include the delivery and recording of very brief advice on smoking in all services. All primary health care professionals should use the ask, advise, act model for provision of very brief advice on smoking.

Measure of success:

A year-on-year increase in the number of health care professionals trained to provide very brief advice.

Data need: Public Health England to collect data and establish a baseline within one year then Taskforce for Lung Health to specify a target percentage increase.



Air quality

Toxic air is one of the most significant public health problems of our time, and it is the largest environmental risk to lung health in England. Everyone should have a right to breathe clean air and doing more to tackle air pollution must be a priority.

Air pollution causes harm to healthy lungs and exacerbates problems for those living with a lung disease. Pollution is linked to up to 40,000 deaths in England every year and costs society more than £20 billion.¹²

The biggest cause of dangerous air pollution in our towns and cities is from road transport.

Recommendation 1c:

Introduce category D Clean Air Zones in the most polluted towns and cities across England

Local authorities should introduce Clean Air Zones in areas of high exposure to pollution. This requires action to restrict the most polluting vehicles to improve air quality, bringing levels of nitrogen dioxide pollution within legal limits. Clean Air Zones can include an area in which vehicles can be charged or fined for entering. Category D zones include private cars as well as buses, coaches, taxis, private hire vehicles, heavy goods and light goods vehicles.

Measures of success:

All 30 cities identified by recent court action to be within legal limits for nitrogen dioxide.

All 30 cities identified by recent court action to have a charging Clean Air Zone in place.

Stopping smoking

Stopping young people from taking up smoking in the first place is critical. One example of how to do this is Cut Films, the education and prevention arm of the Roy Castle Lung Cancer Foundation. Cut Films uses film-making and social media to educate and engage with young people about the harm caused by smoking and tobacco. Launched in 2009, Cut Films now works with more than 4,000 young people each year.

Cut Films supports young people to research the impact of tobacco and smoking. They make a two-minute advert to persuade their friends not to smoke. They share their advert in their local community, campaigning for votes, to spread their anti-smoking messages and to signpost to local stop smoking services. A local Cut Films competition adds to the competitive element.

The project follows NICE public health guidelines and recommendations for smoking prevention in schools and preventing the uptake of smoking in children and young people. 90 per cent of the young people surveyed in 2014–15 felt that the project had made them consider not smoking in future.¹³

Cleaning the air

To help improve air quality, an Ultra-Low Emission Zone (ULEZ) will be in place in central London from April 2019. Most vehicles, including cars and vans, will need to meet new, tighter exhaust emission standards or pay a daily charge within the ULEZ. The plan is to remove the most heavily polluting vehicles from the city to protect local communities.

The area covered by the ULEZ is the same area as the Congestion Charging zone, with plans to extend it to the area bounded by the North and South Circular roads in 2020. It will be clearly signposted with road signs showing where it applies. The ULEZ will operate 24 hours a day, every day of the year, including weekends and public holidays.

The ULEZ is expected to encourage people to use their cars less in central London, and reduce levels of nitrogen dioxide and particulate matter.

Recommendation 1d:

Place new restrictions on particulate matter (PM) emissions from all sources

Toxic particulate matter, or soot, comes from a range of sources including vehicles, wood burning, industry and farming. The smaller the particles, the deeper they can penetrate into the respiratory system and the more hazardous they are to breathe.

Our legal limits are higher than those recommended by the World Health Organization (WHO) and are considered dangerous. The government has made commitments to reduce emission levels. But it must go further and bring WHO limits into legislation.

Measure of success:

No-one in England lives in an area with an annual average level of PM which exceeds WHO recommended limits, as measured by Defra.

Recommendation 1e:

Government to introduce a national system of air pollution alerts with health advice

The government must improve air pollution monitoring and introduce a national system of alerts and health advice.

All kinds of pollution should be routinely monitored, especially around areas where vulnerable people are likely to be such as schools and hospitals.

People should be able to see easily what air pollution levels are like in their local areas so that they can take steps to protect themselves and their families, such as choosing cleaner travel routes or avoiding exercise outdoors on days when pollution levels are very high. Information should be timely and available through digital channels.

Measure of success:

National system of air pollution alerts is set up and implemented within one year of this report being published and evaluated to assess public use and impact on behaviour change within five years.



Agnes Griffiths was a bus driver and conductor in London from 1974 until 2002. "I really enjoyed my job," says Agnes, now 68. "I worked with some great people and I was part of a vital public service."

However, at the age of just 52 Agnes was encouraged by her employer to retire early on medical grounds. She left her job, against her wishes, one year after being diagnosed with COPD. "I suffered chest problems since I was a child. My health deteriorated after the introduction of bendy buses in London. The air conditioning system used recycled air and it exacerbated my condition."

Agnes feels that she could have remained in work for several more years if her

employer had been prepared to make reasonable adjustments. "I had worked all my life and I couldn't cope with having to leave work. I found it very frustrating."

Agnes moved from London to Canterbury. She feels that the cleaner air has been good for her health and she enjoys living closer to her grandchildren. She runs a Breathe Easy group and is a patient representative for the British Lung Foundation.

"I think employers should understand that a diagnosis of a lung condition does not mean that you can no longer contribute or have a role," says Agnes. "Like many people with lung disease, I had so much more to give."

Occupational lung disease

Occupational lung disease continues to contribute substantially to work-related ill health and includes a wide range of life-threatening or adversely life-changing conditions, caused or made worse by exposure to hazardous workplace chemicals, dusts and fumes. Some of these diseases develop shortly after exposure, others many years later. Estimates indicate approximately 12,000 deaths each year are linked to past exposures and there are an estimated 20,000 new cases of self-reported breathing or lung problems annually.¹⁴

There is a need to improve the understanding of what employers and others with responsibility for managing health and safety need to do to comply with the law regarding exposure to hazardous chemicals, dusts and fumes. In addition, there must be effective engagement with health care professionals to enable early identification of work-related symptoms. Training for health care professionals should include support and guidance on identifying the links between high-risk occupations and occupational lung disease.

Occupational lung disease guidance should be updated for all professions where respiratory care is a core component of clinical training. People with breathing problems should be encouraged to talk about their work with their health care professionals.

Information for employers

The Health and Safety Executive Go Home Healthy campaign focuses on raising awareness and promoting prevention, supporting employers to protect workers from work-related lung disease. It features real-life stories, including Terry McGough, 57, a former stone mason from Liverpool and his wife, Christine.

At the age of 51 Terry was diagnosed with silicosis, a severe progressive lung disease caused by breathing in stone dust. Terry spent many years working in confined spaces, with nowhere to get changed or shower. He was not provided with safe protective workwear. Terry says that although he and his colleagues knew that stone dust was not good for them, they were never told how harmful it could be. Terry advises younger workers to always be aware of the potential risks to lung health from their work and to ask employers to provide a safe working environment.

Recommendation 1f: Improve the awareness of and compliance with the Control of Substances Hazardous to Health Regulations 2002 (COSHH) to prevent and control workplace exposures

Many businesses use substances (or products that are mixtures of substances) that can cause harm to employees, contractors and others. There is a misconception that occupational lung disease is a historical problem that has been solved, yet there are still many occupations and high-risk work activities that present risks to lung health, from construction to cleaning and artisan baking. Significant improvements are needed in preventing and controlling exposure, especially in building, manufacturing, quarries, mines, waste and recycling and agriculture. Employers are responsible for ensuring effective measures are in place to control

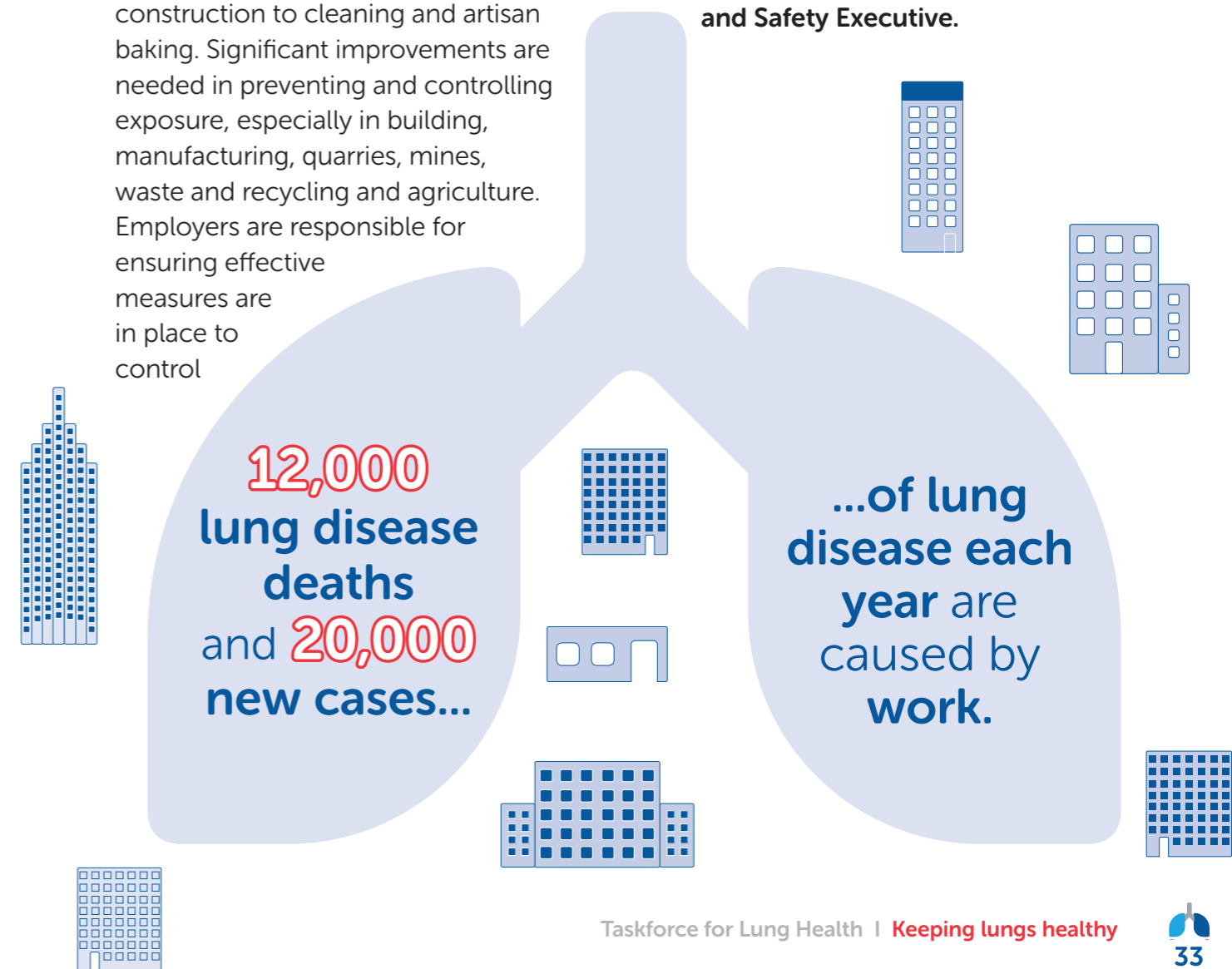
exposure and protect the lung health of their workforce.

Employers should raise the profile of occupational lung disease to highlight its continued prevalence and severity and ensure the safety of their workforce to keep their employees' lungs healthy.

Emphasis must be on prevention of occupational disease. This should be focused on employers and line managers, who are responsible for the health and safety of their staff, as well as the self-employed.

Measure of success:

Reduction in the incidence rate and number of new cases of occupational lung disease as reported by the Health and Safety Executive.



Recommendation 1g:

Embed understanding of occupational lung disease in undergraduate and postgraduate health care professional training and ensure continuing professional development programmes in relevant clinical groups maintain knowledge in this area

Measure of success:

All higher education institutions for health care professional training (undergraduate and postgraduate), where appropriate, have an occupational disease programme identified in their curriculum.

Data need: Data to be collected on the number of respiratory specialist training programmes that include content on occupational lung disease.

Protection for workers

The British Occupational Health Society has created Breathe Freely to raise awareness of lung disease and how to do something about it. The campaign helps employers and employees to understand the health risks, and then improve working conditions.

The initiative is supported by many building companies, such as Brown & Carroll. The company has long enforced a policy that requires an automatic dust extraction system because of the dangers of breathing in wood dust when cutting timber, in particular MDF products. All cutting machines have dust extractors but when small quantities of visible dust in the air and on the surfaces around the cutting stations were reported, it was clear that the risk of exposure to the potentially harmful airborne wood dust particles was not being effectively controlled.

Everyone undertaking cutting works must now wear disposable dust masks as a secondary precaution. Different masks provide different levels of protection depending on the types of dust and everyone's face fit is tested to ensure that these dust masks are worn correctly and are comfortable.

Annual flu vaccination

Recommendation 1h:

Increase rate of flu vaccination among the clinical at-risk groups and front-line NHS and social care staff who have contact with patients

Flu is a potentially fatal lung disease. People with chronic lung diseases are significantly more susceptible to flu and are more likely to need to be in hospital if infected. Vaccination can reduce hospital admissions by up to 52% and reduce mortality by 70%.¹⁵ But vaccine uptake in people with chronic respiratory conditions remains too low, at just 51%. This is despite the fact that immunisation rates in the UK across the general population are high. Around 70% of people aged over 65 typically receive the vaccine every year.¹⁶

The flu vaccine is also recommended for pregnant women as it helps protect both mother and baby. Flu caused one in 11 maternal deaths between 2009 and 2012.¹⁷

About one in 10 cases of flu caught in hospital is fatal, so it is also critical that health care professionals involved in the care of people with lung disease are protected from flu, so they don't run the risk of passing it to their patients.¹⁸ There is evidence that health care worker flu vaccination can reduce sickness absence,



improving the system's ability to cope with winter pressures.¹⁹

In autumn 2017 NHS England unveiled new measures, alongside Public Health England, the Department of Health and Social Care, and NHS Improvement to increase flu vaccination uptake and implement wider contingency plans to respond to winter pressures.²⁰ The NHS aims for 100% of health care workers with direct patient contact to be vaccinated in 2018–19.²¹ Funding was also provided for free flu jabs

for social care staff in contact with people at increased risk of flu, if staff are employed by a registered care or nursing home or home care provider.²² This funding should be continued so that all social care staff are eligible for free vaccination and all health and social care staff with patient contact should be encouraged to have flu jabs.

Data need: Public Health England to start collecting data on flu vaccine take-up among social care staff and to start collecting separate data for flu vaccine take-up among people with asthma, COPD and other chronic respiratory diseases.

Measures of success:

Increase in the take-up rate of the flu vaccine among health and social care staff from 68.7% to 100%.

Increase in the take-up rate of the flu vaccine among people with chronic respiratory disease from 50.8% to 75%.

Fighting flu on the frontline

Birmingham Women's and Children's NHS Foundation Trust has produced several years of strong flu fighter campaigns which have resulted in high uptake. One initiative is called 'Get a jab, give a jab'. The trust committed to match each flu vaccination given to a member of staff with a donation of 10 tetanus vaccinations to a UNICEF project, focused on eliminating tetanus in mothers and babies.

87 per cent of frontline staff across Birmingham Children's and Birmingham Women's Hospitals had a flu jab in winter 2016–17.²³ Staff feedback showed that the campaign was very well received, people felt that it enabled the trust to show its values clearly to others and, in addition to fighting flu, people were confident that having their jab makes a meaningful difference to patients and to a wider community.



Felicity Payne, from Eastbourne, believes her mother died as a consequence of flu that was passed on by one of her carers. "My mother died in March 2014 after catching flu from one of her carers or another health professional," says Felicity. "She was bed-bound and no one else had visited her."

The flu jab should be publicised and made more widely available to prevent infections, particularly for those caring for the elderly, Felicity says. "People like my mother, with weakened immune systems, rely on carers coming in to help and should not be exposed to infection."

Felicity, 62, was offered a flu jab for the first time four years ago when she went to a chemist after suffering several nasty

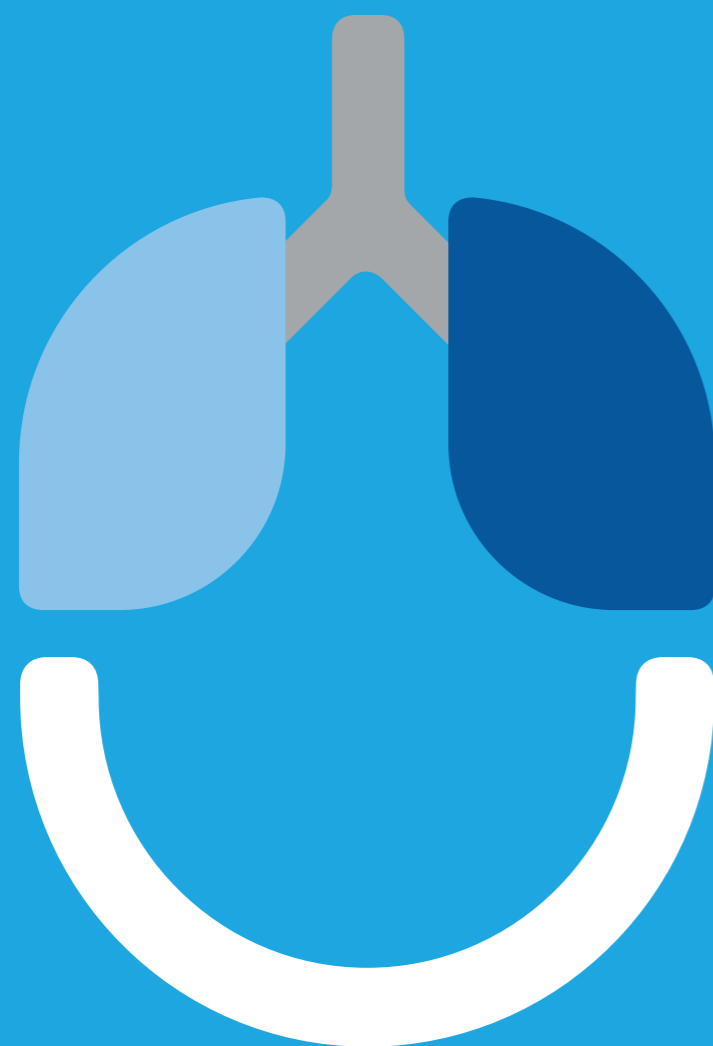
chest infections. Felicity believes that the first infection was also probably caused through contact with one of her mother's paid carers.

Felicity has since been diagnosed with COPD and feels that her poor lung health can be traced back to those earlier infections because until then she had enjoyed very good health. Felicity quit her job as a teacher two years ago because of her health and the risk of exposure to infections.

Felicity says: "I have only had one bad chest infection since I have been having the flu jab. I will continue to have it because it gives me the best chance of not catching flu."

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Chapter 2: Identifying lung disease early

Early and accurate diagnosis is critical to improve health for people with lung disease. Identifying the disease at the earliest stages offers the best chance to take measures to slow its progression, which could add years to people's lives and improve their quality of life significantly.

All people with lung disease should be able to expect the same timely and accurate diagnosis as people with cancer. Not everyone with symptoms will be found to have a lung disease that will seriously shorten their life, but some will. Nine out of 10 people who are referred to a cancer specialist turn out not to have cancer but because the ambition is for everyone to be seen quickly, diagnosis and treatment have improved and where possible those serious illnesses can be caught early with profound effects for people with cancer and their families.¹

Diagnosing lung disease at an earlier stage gives people the opportunity to make changes to their lifestyle, such as quitting smoking and becoming more physically active, which are both factors associated with lower mortality.^{2,3} One of the most dispiriting issues for people with lung disease and their families is knowing that better treatment might have been possible if they had been diagnosed sooner.

Many people with lung disease remain undiagnosed or misdiagnosed for years and only learn of their condition when it is too late for effective treatment. Almost half of lung cancers are diagnosed at stage 4, when survival rates are poor. In fact, 35% of cases are diagnosed when people present as an emergency because they are so unwell.⁴ There have been missed opportunities for diagnosis, so those people with lung cancer never get onto the cancer pathway at the right time. They come to it very late.

There's a problem with both underdiagnosis and misdiagnosis of lung disease. It is estimated that there are more than one million people living with undiagnosed chronic obstructive pulmonary disease (COPD) – the 'missing millions'.⁵ The National Asthma and COPD audit in Wales 2014–15 found that where spirometry had been performed in a COPD diagnosis, in a quarter of cases the results were not consistent with COPD, suggesting a significant rate of misdiagnosis.⁶

Many people who are in the process of being diagnosed wait too long for test results because of delays. Every year more people are referred for diagnostic tests and services are struggling to keep up with growing demand. People suffer anxiety while they wait, and follow-up appointments and treatment are delayed even as the disease advances.

Patients also have to deal with many different NHS specialists and departments, often located in different hospitals and health centres and in different towns.

Communication between these departments can be poor and progress can depend on the ability and determination of a person and their family to demand attention. Those who are unable to cope with a complex system, or are too ill or vulnerable, get left behind.

We acknowledge that for some people living with aggressive lung disease, we don't yet have any treatments available to slow or limit the effects of their condition. But people with lung disease feel strongly that they have a right to know what is wrong with them as soon as is possible so they can take advantage of any treatments that will improve their quality of life and make the most of the time they have left.

Recommendation 2a:

Create a clear patient pathway with services for timely, accurate and complete diagnosis for all people with breathlessness and other respiratory symptoms

To address the problems with late and inaccurate diagnosis, there should be clear, time-limited targets for all lung diseases in line with the ones already in place for cancer. GPs, general practice and community pharmacy staff, physiotherapists and other health professionals must have a clear set of steps to take when a person presents. Practices should have access to timely quality-assured diagnostic tests. People can be referred to a multi-disciplinary breathlessness team or to a specialist for diagnosis when necessary. There must be a clear pathway for respiratory patients to follow, which identifies all lung diseases early, offers timely diagnoses, and allows people with lung disease to get the treatment and support they need. The diagram below shows how such a pathway could work.

For some diseases, we are a long way off being able to diagnose and begin treatment within 62 days. Some diagnostic tests for interstitial lung disease (ILD) need serious surgery and we have a national shortage of specialist staff. However ambitious this target, for people diagnosed with ILD, both they and health care professionals would like to see positive improvement within five years.

Measures of success:

93% of patients to be referred to a specialist if appropriate within two weeks and 96% to start treatment within 31 days of a diagnosis and with a package of care agreed, in line with NHS England cancer targets.

85% of patients to begin their first treatment within 62 days of an urgent GP referral, in line with NHS England cancer targets.

Data need: NHS England to establish baseline data for speed of respiratory diagnosis and referral within one year.

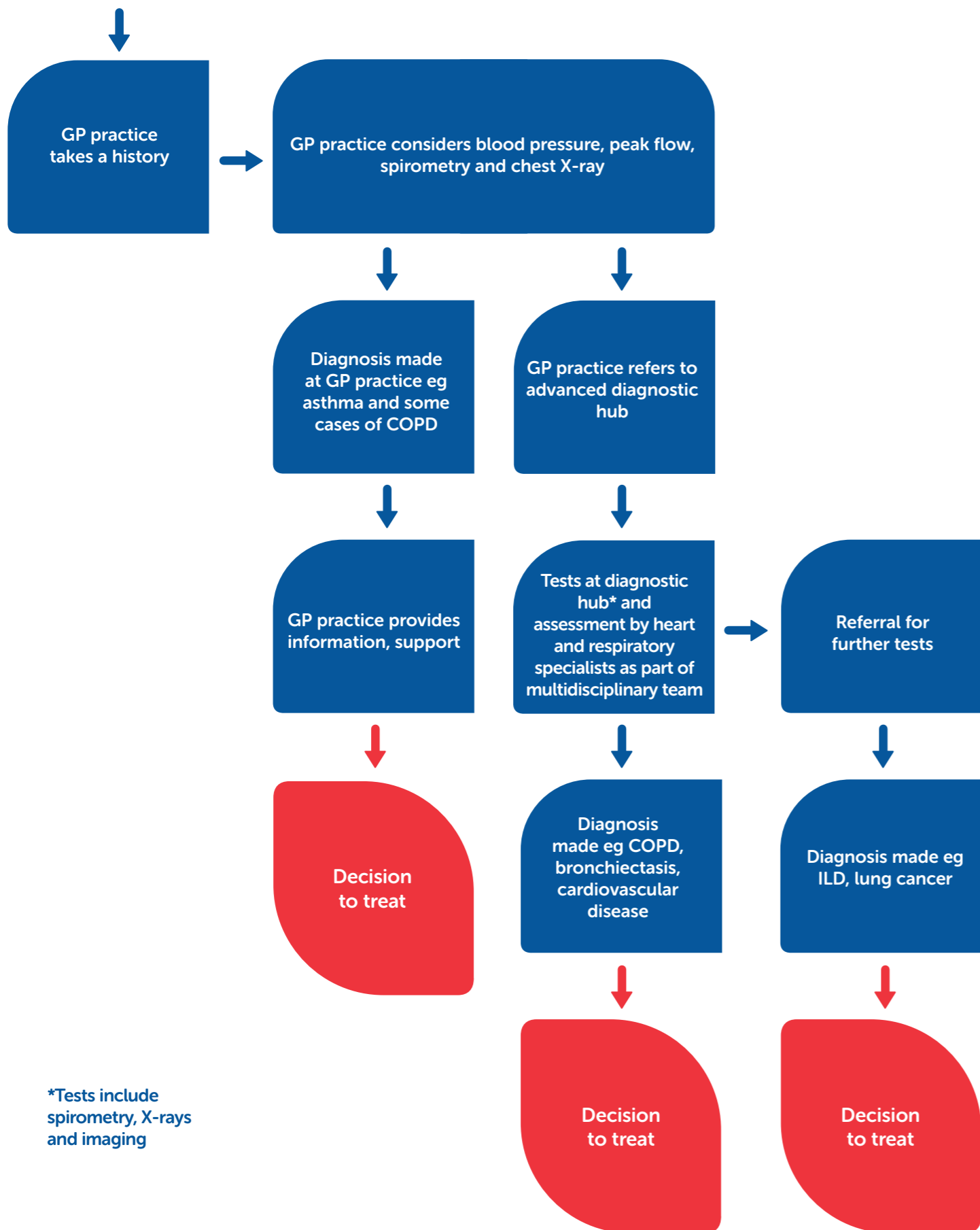
Basic breath test for diagnosis

Spirometry is used to tell if breathing is obstructed by narrowed or inflamed airways. The results are useful in diagnosing lung conditions such as chronic obstructive pulmonary disease (COPD) and asthma. It can also be used to grade the severity of conditions.

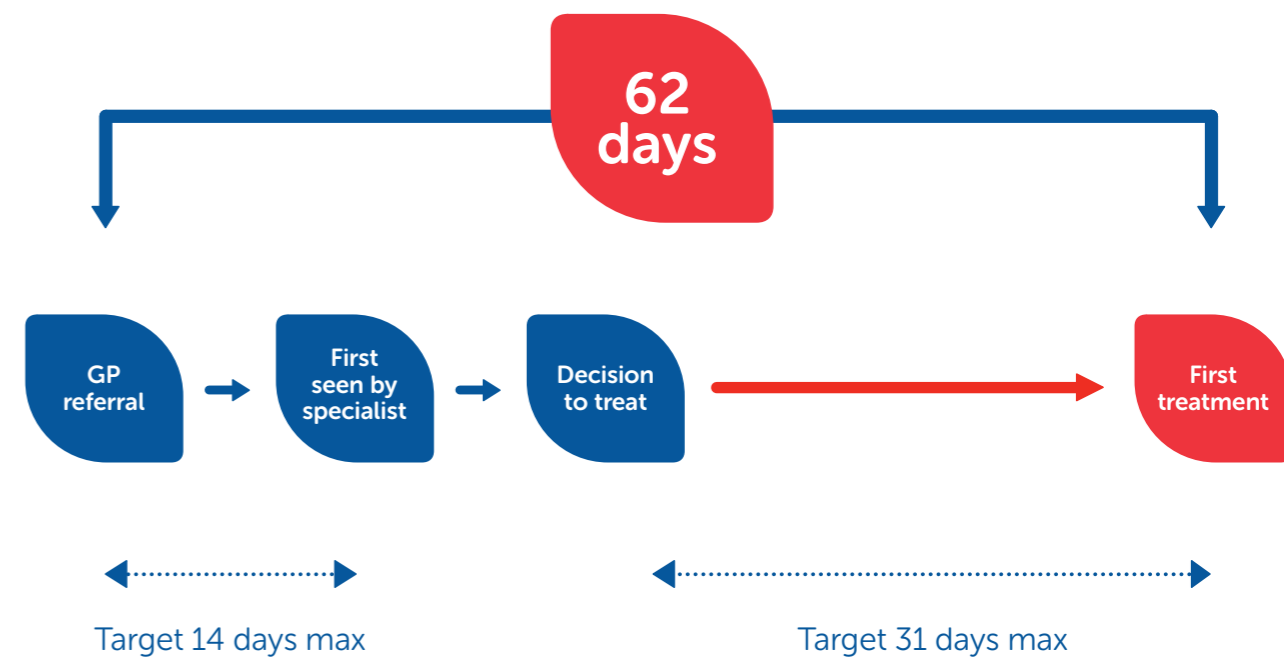
Spirometry measures the total amount of air you can breathe out from your lungs and how fast you can blow it out. It can help to assess if inhaled medication can open up your airways by reversibility testing. This is when your health care professional asks you to use your inhaler or other medication, wait some minutes, and then repeat the test. A spirometry test usually takes less than 10 minutes but will last about 30 minutes if it includes reversibility testing.

Person goes to GP practice with respiratory symptoms like chronic breathlessness, cough or persistent chest infection

Lung disease diagnosis pathway



Maximum time for GP urgent referral for suspected aggressive lung disease



Better diagnosis

The National Optimal Lung Cancer Pathway, which should be fully implemented in all parts of the country, provides a model for an effective and efficient lung cancer pathway.⁷ Its key features are chest X-ray to CT scan and clinic in less than 24 hours; scope for primary or secondary care to lead up to triage; faster turnaround times for testing and reporting; and daily respiratory clinic opportunities.

One-stop shop for diagnosis

University Hospitals Leicester NHS Trust has taken part in a pilot programme to improve the speed and accuracy of diagnosis in people with symptoms of breathlessness in Leicestershire and Rutland.⁸ The approach involved a specialist-led diagnostic clinic for both cardiac and respiratory causes of breathlessness, providing a one-stop diagnostic shop in a secondary care setting for people referred from primary care. The clinic achieved a marked improvement in earlier diagnosis compared to historical data, and access to physiotherapy was speeded up by having a physiotherapist on site.

The trust surveyed 10 people who attended the breathlessness clinic and respondents rated the care as excellent and indicated that they were treated with respect and dignity. People had more confidence in their diagnosis and treatment because they could see they were being treated by a team working together. They were better able to understand and accept their diagnosis because they received consistent messages from different professionals on the same day. They received care from health care professionals with a keen interest in tackling breathlessness as a symptom.

// If I had received help earlier, I'm sure some of the damage could have been avoided

Almost a decade after first reporting the symptoms to her GP, Liz Ames [name changed], from London, was diagnosed with bronchiectasis, a disease in which there is permanent enlargement of parts of the airways of the lung.

Liz, then an active runner, began to suffer from a severe cough, which her doctor insisted was related to her existing asthma. She says: "I could tell that there was more to it."

She challenged her GP's diagnosis and eventually was referred to a specialist at her local hospital, who agreed with her GP without carrying out a CT scan, and did not offer additional treatment, such as physiotherapy or chest clearance techniques to alleviate her coughing. "We may just have to leave it be," the consultant told Liz.

It was not until Liz insisted on being referred to the Royal Brompton Hospital that she was diagnosed with bronchiectasis and chronic pseudomonas infection.

Liz, now 41, says: "If I had received help earlier, especially from respiratory physios, I am sure some of the damage and perhaps also the pseudomonas infections could have been avoided."

"Patients should be taken seriously when they first report lung-related problems to their GP."

Recommendation 2b:

Develop a formal referral system to enable community pharmacists to refer people directly to general practice or other appropriate organisations

More than 1.6 million people visit a community pharmacy each day, providing a huge opportunity to pick up on warning signs for lung disease which can then be referred to GPs.⁹ People who are buying a lot of over-the-counter products like cough medicines or nasal sprays could have an undiagnosed respiratory disease.

Pharmacists are also in a good position to talk to people about their wider lung health when they visit the pharmacy for stop smoking services or flu vaccinations. Medicines Use Reviews (MURs) offer an opportunity for pharmacists to identify people not responding to medicines, and those on frequent courses of antibiotics and corticosteroids with no confirmed diagnosis.

Community pharmacists must be included in respiratory pathways and recognised as valuable health care professionals who can identify and support people at risk of developing lung disease or those who are already being treated.

NHS Digital is currently working to allow electronic information to flow between community pharmacies and GP practices, but this is only focused on information regarding flu vaccinations. Information sharing must go further than this.

New diagnostic models

People due to receive a CT-guided lung biopsy are generally booked into a day-care or inpatient bed. This can lead to significant delay in access to lung biopsy. But an alternative diagnostic pathway has been established by the Royal Free London NHS Trust using ambulatory lung biopsies.¹⁰

The service is delivered by the hospital's radiology department on an outpatient basis, using the same procedure as a conventional NHS lung biopsy but completely avoiding the use of hospital beds. The person receives a chest X-ray 30 minutes after biopsy and is discharged. This allows 99% of patients to be discharged within one hour.

The approach allows for a 10-fold increase in the number of biopsies. The service has performed more than 1,500 outpatient biopsies since 2011. It saves 3.5 to 5.5 bed hours for uncomplicated biopsies and £400 a day for people with a significant lung collapse, who previously would have occupied a bed as a result. Even those with severe lung collapse do not need to be admitted to hospital.

Community pharmacists should be able to refer people onto appropriate care.

Measure of success:

A formal system for community pharmacists to refer people with suspected lung disease to general practice to be developed and implemented across England.

Getting a diagnosis at the chemist

A pilot project involving 21 community pharmacies in the Wirral area found that there are significant benefits to people at risk of developing COPD, as well as cost savings, through case-finding by screening.¹¹ The pharmacies provided a case-finding service for six months, using a symptom questionnaire and spirometry test of lung function.

A total of 238 people identified as either smokers or regular purchasers of cough medicines were screened. More than half (56.7%) were identified as at risk of COPD. People were given general lifestyle advice, including advice about smoking cessation services. According to an evaluation, if the Wirral findings were replicated in England, case-finding would identify more than 205,000 people at risk of COPD and achieve savings of around £215 million.

Recommendation 2c:

Develop a single consistent guideline for diagnosis and management of asthma, including referral to tertiary services as appropriate for difficult or suspected severe asthma and ensure appropriate resources for implementation

There are an estimated one million people living with difficult asthma in the UK, of which 200,000 are suspected cases of severe asthma.¹² But only 1,000 people with a confirmed diagnosis are on the severe asthma registry.¹³ Referrals to specialist care vary significantly, with many people with possible severe asthma missing out, and there are currently no clear and consistent national referral criteria for difficult or severe asthma.

Diagnosis of severe asthma is complicated because asthma-like symptoms can be caused by several other conditions. Diagnostic tests that can accurately and objectively differentiate between them have yet to be developed.

Primary care clinicians often do not get the full picture of someone's asthma exacerbations, and can miss suspected cases of severe asthma, because information is not always available from hospitals.

Different national guidelines for asthma diagnosis and management are now available from two sources: the National Institute for Health and Care Excellence (NICE) and the British Thoracic Society (BTS). These require different tests, which

is unhelpful to GPs and secondary care specialists and may adversely affect patient care.

There should be a single consistent guideline for the diagnosis and management of asthma. This must include clear guidance on how to identify and deal with severe asthma. In the meantime, health care professionals are urged to consult the consensus statement from the Primary Care Respiratory Society which highlights similarities and differences between BTS and NICE asthma guidelines and advises how to proceed where there are discrepancies.¹⁴ They should also consult the practical response for secondary care professionals produced by BTS.¹⁵

Measure of success:

A single guideline for the diagnosis and management of asthma is jointly developed by NICE, the Scottish Intercollegiate Guidelines Network (SIGN) and BTS.

Recommendation 2d:

Introduce targeted case-finding for people who have symptoms suggestive of chronic obstructive pulmonary disease (COPD) in general practice, with follow-up care and services

Diagnosing COPD at an earlier stage would give people the opportunity to get treatment and make changes to their lifestyle, such as quitting smoking and exercising, that could add years to their life. However, due

to the gradual progression of COPD, many people remain undiagnosed for years. While 1.2 million people are living with diagnosed COPD, many more have yet to be diagnosed and receive no treatment even as their condition deteriorates.¹⁶

Case-finding should take place in general practice to identify people who may be at high risk of COPD. This includes those with a history of smoking, of asthma or bronchitis, and those with frequent chest infections. At the moment, many opportunities to diagnose COPD in a timely way are being missed.¹⁷

The case for targeted case-finding is strong. A trial found that targeting people who have smoked for most of their lives was seven times more effective than usual care at identifying new cases of COPD, confirmed by spirometry.¹⁸

Measures of success:

All GP practices to be actively case-finding for COPD, to be reported by CCGs.

Increase in people registered as having COPD by 1 million from just under 1.1 million in 2016–17 to 2.1 million, using the Quality and Outcomes Framework (QOF) data currently available.

Data need: National Asthma and COPD Audit programmes to replicate, as far as possible, the primary care audit (Wales) in England to collect more accurate data on number of people with COPD, identified in primary care, from 2019.

Finding people with COPD

Two GP practices in Hampshire took part in a pilot project to investigate the benefits of case-finding for COPD and asthma. Clinics were held at a patient's own GP practice. A search of patient records identified people with a history of smoking who had also been prescribed an inhaler within the previous 12 months, or had been hospitalised with a respiratory infection, or had presented with unexplained respiratory symptoms.

People with symptoms but without a diagnosis were invited to a clinic led by a respiratory specialist nurse, where full diagnostic spirometry and a respiratory assessment were carried out. The nurse suggested a potential diagnosis and recommended further treatment or referral to the GP where appropriate. The nurse also provided treatment, such as smoking cessation advice, where clinically appropriate.

A report into the project found that the clinics had demonstrated how specialist expertise can be provided in primary care without the need for extensive, expensive secondary care technologies.¹⁹

Recommendation 2e:

Implement a comprehensive national lung cancer screening programme, targeting those at high risk of developing lung cancer, and offering them low dose CT screening

There is strong evidence that a national lung cancer screening programme aimed at high-risk groups would be a cost-effective way to improve early diagnosis. It would also identify people with other lung diseases.

Survival for people with lung cancer is closely linked to the stage at diagnosis. When diagnosed at earliest stage, more than one in three people with lung cancer will survive their disease for five years or more, compared with around five in 100 people when diagnosed at a later stage. Earlier diagnosis will contribute to improved survival rates for people living with lung cancer.

The US National Lung Cancer Screening Trial (NLCST), the world's largest cancer screening trial, showed a 20% reduction in lung cancer deaths and a 6.7% reduction in deaths from any cause by scanning people at risk of lung cancer each year.²⁰ The UK Lung Screening Trial (UKLS) also showed that screening detects lung cancer at an early stage, with curative surgery offered to more than 80% of people.²¹

It is vital that, while we urgently build the national lung cancer screening programme, we continue to fully support and roll out current lung health check projects.

Measures of success:

Decrease in the number of patients diagnosed with lung cancer at stage 3 or 4 from 67% to the future benchmark established in the International Cancer Benchmarking Partnership SURVMARK-2 project (due in early 2020).

Survival rates for lung cancer to double at one year (from 39% to 78%), five years (from 16% to 32%), and 10 years (from 4.9% to 9.8%).^{22, 23}

// I honestly feel as though this lung health check saved my life

Michael Brady, 64, is a retired factory worker from Harpurhey in Manchester. He was diagnosed early with lung cancer after attending a lung health check at a mobile CT scanner unit parked at his local shopping precinct. Checks were being carried out as part of a pilot project led by the Macmillan Cancer Improvement Partnership in Manchester (MCIP), in collaboration with the lung cancer team at the University Hospital of South Manchester (UHSM).

Michael was already being treated for COPD and had regular X-rays to monitor his condition. He was invited to attend the lung health check as he was aged between 55 and 74, had previously smoked and was registered with a participating GP practice.

Michael says: "I was scanned on the Tuesday there and then at Harpurhey Precinct and then I was sent a hospital appointment and attended that within a week of my lung health check. The doctor told me that they'd found a cancer in one of my lungs that was about the size of a pea. He said that it could be got rid of by radiation therapy and that I wasn't to worry.

"I know I've got cancer and it is scary, but I'd rather know. I know what I'm dealing with and I'd rather know now than in a few months or years when it will be too late. I honestly feel as though this lung health check has saved my life."

Michael has since undergone radiation treatment at The Christie NHS Foundation Trust, Manchester.



Margaret Storey lives with COPD, which went undiagnosed and untreated for many years. By the time she received a formal diagnosis her lung capacity had fallen to just 15%. Five years earlier she had been admitted to hospital with pneumonia, but doctors did not identify the primary cause of her ill health, nor warn her about COPD.

“I am not blaming anyone,” says Margaret, from Sunderland. “My COPD was caused by smoking and smoking was my choice. But if at the time of my first encounter with chest specialists they had been totally honest with me and gave me good written information about my condition, I would have taken steps to manage my health in a different way.”

Five years after her initial hospital admission, Margaret was again taken

ill. This time doctors diagnosed COPD. Although they spoke to her about her condition, it was through reading a letter sent to her employers explaining the extent of the damage to her lungs that she truly understood how ill she was. “At hospital it was so difficult to take everything in, but seeing it written down like that in plain English was easy to understand.”

Margaret stopped smoking immediately, and in the 13 years since her diagnosis her condition has not deteriorated. Today at the age of 72, and on oxygen, Margaret does what she can to campaign to raise awareness of COPD. “Lung disease isn’t prioritised like cancer or diabetes. If health professionals thought of lung disease in the same terms we could do more to prevent it or diagnose it earlier.”

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Chapter 3:
**Better care
for all**

The UK has some of the worst outcomes for lung disease in the developed world and there has been no improvement for more than a decade.¹

Lung disease is one of the three biggest killer disease areas in the UK, alongside heart disease and non-respiratory cancers.² It kills 115,000 people each year, the equivalent of one person every five minutes. These mortality figures are roughly the same as those reported by the British Thoracic Society (BTS) a decade ago. The UK has the fourth highest mortality rate from lung disease in Europe.³

There is much more that we need to understand through research about the causes and best possible management of lung disease. But we already have evidence-based, effective management, both drugs and non-pharmacological, which are not always available to patients when they need them, even though they may provide improved quality of life and more years of life. This is in addition to treatments for tobacco dependency such as stopping smoking. Access to treatment can depend on where you live and whether your health care professionals are well-informed about the best ways of treating lung disease.



Surgery

Recommendation 3a:

Establish clear best practice in assessment, referral and regular monitoring of all people who would benefit from a lung transplant

A lung transplant can significantly extend a person's life expectancy while also improving their quality of life. However, the number of lung transplants every year is still low, with 167 transplants in the UK in 2016–17.⁴ This is despite advances in surgical procedures and an increase in the number of donor organs. About 24% of people waiting for a transplant will either die on the waiting list or be removed because they are too frail.⁵

Standardisation around referral practice must be developed.

115,000
people die
from lung disease
each year.

That's one person
every 5 minutes.

People on the active waiting list should be supported to ensure that they are physically and emotionally prepared when a suitable donor lung becomes available.

Measure of success

An increase in the number of people living with a lung disease receiving an annual review at a transplant centre, as monitored by NHS trusts.

Data need: NHS trusts to publish transplant review data on an annual basis.

Surgery to improve breathing

Lung volume reduction surgery is an operation to take out the worst affected areas of the lungs so that the healthier parts can work better. By removing the most damaged parts of the lung, which are baggy and trap air, the person can exhale to a more normal level and breathing is more comfortable.

Lung volume reduction surgery is suitable for only 1–2% of people with COPD.⁶ This is a significant operation and in carefully selected patients it can improve breathlessness, how far people can walk and even increase survival.

Recommendation 3b:

Establish clear best practice in assessment, referral and regular monitoring of people with advanced chronic obstructive pulmonary disease (COPD) and advanced breathlessness who would benefit from a lung volume reduction procedure

Lung volume reduction procedures for people with emphysema, one of the lung conditions described by COPD, can improve lung function and quality of life. Newer and less invasive lung volume reduction technologies, such as valves, may broaden the pool of eligible people. Despite this, lung volume reduction procedures remain an underused therapy. Some 16,300 people in England could be eligible but only around 100 procedures are performed a year.^{7, 8, 9} Referral is not routinely considered for all patients and frequently those who would benefit must fight to be considered for lung volume reduction procedures. A national network of specialist multi-disciplinary teams who can assess people with advanced COPD is needed.

Measure of success:

All people with advanced COPD who may benefit to undergo tests to assess lung volume. All those with significant lung hyperinflation to be referred to a multi-disciplinary team for consideration for lung volume reduction procedures.

Recommendation 3c:

All surgery units to employ enhanced recovery after surgery (ERAS) guidelines with a specific focus on lung health

Studies show that ERAS reduces the number of days spent in hospital and the risk of complications after surgery. These programmes allow a multi-disciplinary team to make a large number of relatively small improvements along the entire surgical pathway, from referral through to recovery.

Currently ERAS is used commonly for some types of cancer (breast, colorectal) but not yet routinely for lung surgery. ERAS should be deployed across all surgery units that operate on people with lung disease, as part of a perioperative care pathway.

Measure of success:

All lung surgery units to implement Enhanced Recovery After Surgery as part of a perioperative care pathway, to be reported by NHS trusts.

Ahead of surgery, there is a real opportunity for individuals to make healthy changes to their lives that can improve treatment outcomes and help to avoid the need for repeated hospital care in the future.^{10, 11} With support to 'prehabilitate' before surgery and rehabilitate after surgery, evidence shows that patients can get home from hospital sooner and in a better condition. This 'prehabilitation' to rehabilitation model is central to perioperative medicine, aiming to provide a seamless journey for people from the moment surgery is first thought about through to a full recovery.

There is a risk of serious complications following lung surgery and people can take a significant amount of time to recover from a lung operation. Evidence demonstrates that Enhanced Recovery After Surgery (ERAS), as part of a perioperative care pathway, can reduce the risk of complications and improve outcomes, including shortening length of stay after an operation.

ERAS is an evidence-based programme that includes the use of minimally-invasive surgery when possible, analgesia protocols, perioperative rehabilitation and interventions such as physiotherapy and smoking cessation, where clinically appropriate.

Getting in shape for an operation

In 2010, the thoracic surgical unit at Bristol Royal Infirmary was one of the first units in Europe to adopt an Enhanced Recovery After Surgery (ERAS) pathway for patients requiring lung cancer surgery. At the time, ERAS guidelines revolved principally around colorectal surgery. The goal was to develop similar care to achieve early recovery for people undergoing major thoracic surgery.

ERAS requires the entire patient pathway, from referral to recovery, to be broken down into component steps and each step improved based on evidence. In Bristol, investment in a sophisticated preoperative assessment unit became the cornerstone for the development of the thoracic ERAS pathway.

Around 1,400 people being treated for lung cancer who come through the Bristol unit have been on an ERAS pathway. Improvements have

included getting fit for surgery, education, smoking cessation and one-stop preoperative assessment clinics. People are admitted on the day of surgery and given carbohydrate loading. They walk to the operating theatre. Minimally-invasive surgical techniques are used along with very short-acting anaesthetic agents. Pain relief and nausea control is focused on minimising side effects and getting people moving. Drains and monitoring are kept to a minimum, and patients have diaries with daily activity milestones and a predicted date of discharge. The results have been impressive with a reduction in postoperative complications and a halving in the length of hospital stay.

Medication

Recommendation 3d:

Improve inhaled therapy, by developing a clear pathway for accurate prescribing and adherence, and promoting new technology such as smart inhalers

In addition, smart devices for asthma are becoming increasingly available – particularly smart inhalers which can objectively track, monitor and prompt medication use. These are Bluetooth-enabled devices that detect inhaler use, remind patients when to take their medication, and gather data that can guide care. Smart inhalers could revolutionise care by managing long-term conditions at scale; enhancing supported self-management; supporting risk stratification; personalising care; reducing avoidable emergency admissions; and improving patients' safety and quality of life.¹⁵

However, barriers to their adoption must be removed. Several manufacturers have market-ready smart inhaler devices, but currently no universal funding mechanism exists for this technology to be readily provided to patients within the NHS. Health care providers should prepare now so that people who want them can benefit from smart inhaler technology at the earliest opportunity.



We spend hundreds of millions of pounds each year on inhaled therapies for lung disease. It's vital that we ensure that the right patients are receiving the right medication and that they know how to use their inhalers properly. The evidence, so far, is that this is not happening.

Dr Nick Hopkinson, clinical lead for chronic obstructive pulmonary disease at Royal Brompton Hospital

Using medication properly is key to controlling symptoms so people diagnosed with lung disease can live their lives as they wish. Inhalers are a vital part of treating COPD and asthma but there are significant problems with their use. A recent systematic review suggests that three-quarters of people make errors using their inhaler devices and that this has not changed over 40 years.¹² Over-reliance on short-acting reliever inhalers is responsible for a high proportion of avoidable asthma deaths.¹³ It is likely that fewer than half of people with COPD using inhaler therapy received an inhaler technique check in the last 12 months.¹⁴

Helping people with lung disease use their medication properly is key to controlling symptoms, so they can live their lives as they wish. It is vital that all relevant health care professionals are trained and upskilled in inhaler use and technique in order to do this effectively. Community pharmacists in particular can play a vital role, with regular checks on people to see if medication is having the intended effect and helping with correct use of their inhalers.

Measures of success:

An increase in people living with COPD who use inhaled therapy receiving an annual inhaler check, aiming for 75% within one year and 90% within five years.

Data need: National Asthma and COPD Audit programmes to replicate, as far as possible, the primary care audit (Wales) in England to collect more accurate data on the proportion of people with COPD receiving an inhaler check, from 2019.

An increase in people living with asthma who use inhaled therapy receiving an annual inhaler check from 76% to 90%, as measured through Asthma UK's Annual Asthma Survey.

Recommendation 3e:

The government and pharmaceutical industry should work together to improve access to antifibrotic drugs for idiopathic pulmonary fibrosis (IPF), cystic fibrosis transmembrane conductance regulator (CFTR) modulators for cystic fibrosis and monoclonal antibodies for severe asthma

For some lung conditions, new drugs have recently been introduced to slow down disease progression. Due to the relatively high costs of these drugs, England's current medicines appraisal systems often end up restricting access. Current examples of this are medicines to treat idiopathic pulmonary fibrosis, cystic fibrosis and asthma.

Idiopathic pulmonary fibrosis (IPF) is a life-shortening progressive condition for which there is no cure. Two antifibrotic drugs are available which can slow down disease progression, helping to improve quality of life. But under NICE guidelines they are only available to patients with lung function of between 50% and 80%, which means that patients in the early stages of disease and more advanced stages are not eligible. The UK is the only country worldwide to impose this restriction. In addition, in England these IPF antifibrotic drugs can only be prescribed at specialist centres, which are not accessible to all patients. In contrast, in Scotland and South Wales any respiratory physician can prescribe antifibrotic drugs for their IPF patients after approval by discussion at a regional multi-disciplinary team

meeting. Specialised advice on prescribing needs to be more readily available to non-specialist clinicians involved in treating and caring for lung disease patients.

Cystic fibrosis is a progressive and life-limiting genetic condition. Last year, half of all people who died with cystic fibrosis were under the age of 31.¹⁶ The drug pipeline for cystic fibrosis is highly promising, with therapies increasingly targeted at a patient's genetic make-up, tackling the root cause rather than the symptoms. There are significant reductions, across the population, in risk of death, need for transplantation and hospitalisation, as well as lower prevalence of complications and infection, for patients on CFTR modulators.¹⁷

Some CFTR modulators have been shown to slow decline in lung function by 42% and cut the number of infections requiring hospitalisation by 61%.¹⁸ However, such drugs present affordability challenges because patient numbers are small. This presents a challenge to NICE's value-for-money criteria for funding, in common with therapies for other rare diseases. The government needs to ensure that reimbursement arrangements are in place with drug companies to make these drugs available.

Monoclonal antibodies (mAbs) are injectable, biologic treatments for severe eosinophilic asthma that can be used as an alternative to oral steroids. They work by blocking the activity of some of the immune system chemicals that trigger inflammation in the airways. These treatments can be effective for relieving debilitating asthma symptoms without the risk of long-term toxic side effects that oral steroids pose. NICE have approved some of these drugs for severe asthma treatment but referral rates

for these new treatments are low. This may be because non-steroid-based treatments for severe asthma are still relatively new and many health care professionals may not know if their patients could benefit from the new treatment options.

Limited access to specialist centres is also a barrier. Developing guidelines for difficult and severe asthma, supported by a targeted awareness-raising campaign, would help primary care doctors and nurses become more aware of the treatments available.

Measures of success:

Prescribing criteria for antifibrotic drugs to have changed in NICE guidelines to match European patient eligibility.

Access to cystic fibrosis transmembrane conductance regulator (CFTR) modulators for cystic fibrosis to be in line with European average.

An increase in the number of appropriate severe asthma referrals to specialist centres, as measured and reported by severe asthma multi-disciplinary teams (MDTs).

Data need: MDTs to publish annual data on appropriate referrals for people with severe asthma with a baseline established within one year.



Ron Flewett, 57, has idiopathic pulmonary fibrosis. He was diagnosed in 2014, with a prognosis of living between three and five years if untreated. He says that the side effects from his medication, which include fatigue, loss of appetite and nausea, are severe. But he believes he would not be alive today without it.

"I came off the drug for six months because of the side effects and during that period I lost 9% of my lung capacity, which is as much as I lost in the previous three years." Ron, who lives near Lincoln,

resumed taking his medication, which he says has changed his life. Aided by oxygen, Ron says he is completing his bucket list. "I get very tired, I'm often in bed by 8pm and don't get up until 10am. Sometimes after a very busy day I may not surface at all."

Two antifibrotic drugs are licensed for use in IPF in England. They both slow down the development of scar tissue in the lungs. But neither drug is a cure.

Oxygen therapy guidelines

Recommendation 3f:

Fully implement British Thoracic Society (BTS) home oxygen therapy guidelines to improve use of home and ambulatory oxygen. Fully implement the National Institute for Health and Care Excellence (NICE) quality standard on idiopathic pulmonary fibrosis (IPF) to ensure people have access to beneficial home and ambulatory oxygen therapy

Oxygen therapy, used in the home or on the move (ambulatory), can make a profound difference to the quality of life for people with lung conditions whose blood oxygen levels are low. However, it is not always accurately prescribed. This means that around one in three people who have been prescribed home oxygen do not benefit from it. Conversely, around 20% of people with COPD would benefit from home oxygen but are not prescribed it, despite links to lower mortality and fewer days in hospital.¹⁹

Guidelines have traditionally been based on COPD so there is a lack of clarity over the circumstances in which people with IPF would benefit from oxygen. The NICE quality standard, requiring people with IPF to

be fully assessed for home and ambulatory oxygen, should be implemented in full.²⁰

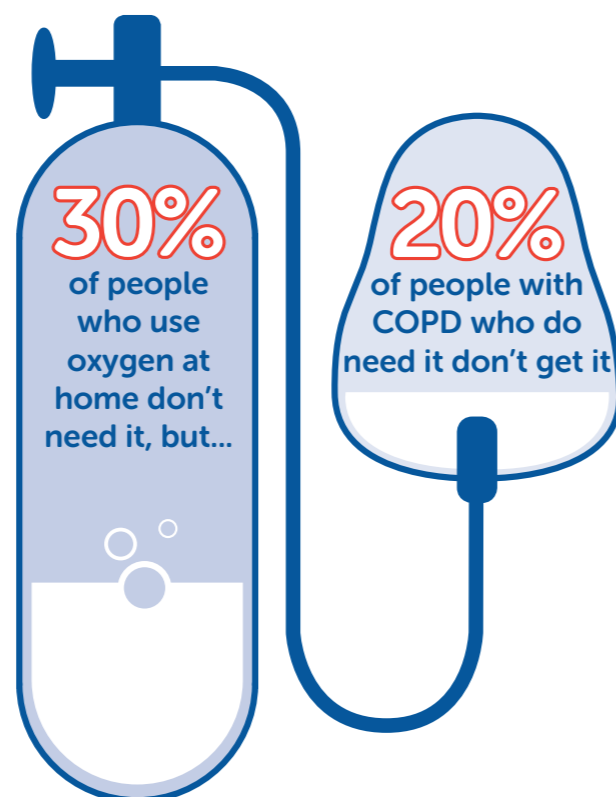
BTS guidelines on appropriate oxygen prescribing and use should be implemented. The Respiratory Futures website hosts resources to help health care professionals and commissioners do this.

Measures of success:

All IPF specialist centres to be routinely assessing patients on presentation for long term and ambulatory oxygen therapy, as monitored by the British Thoracic Society (BTS) IPF Registry.

An increase in the number of people using home and ambulatory oxygen according to the BTS home oxygen therapy guidelines, with a baseline established through the National COPD and Asthma Audit programme.

Data need: Audit of oxygen use according to prescribing guidelines to be collected through the National COPD and Asthma Audit programme to establish a baseline.



Debra Barlow contracted varicella pneumonia at the age of 41. This caused extensive damage to her lungs, resulting in pulmonary fibrosis. After a lengthy stay in hospital, ventilated and in an induced coma, she was discharged. She spent nine years on oxygen 24/7 until she received a double lung transplant in 2015.

Debra, who lives in Nottinghamshire, says that when she was on oxygen she fought a constant battle to obtain optimal equipment and supplies. "Suppliers seemed to have the view that 'we've given you oxygen so what more do you want?' It always was up to me to know about the latest equipment and to ask them for equipment I was entitled to."

"Having a lung disease is extremely tiring and finding the energy to chase up or argue with an oxygen supplier is a challenge." Debra, now 53, says her experience in nursing and social work was a real asset, but she understands why other people without her knowledge would find it extremely difficult.

Debra says that provision for people with a lung condition is mostly designed for the elderly, excluding younger people. "I was focusing on improvement and getting my life back, not just on fighting off infection," she says. "Younger patients like me have different needs and expectations."



You make an adjustment to what you are able to do

Julie Reynolds has lived with asthma since childhood. She was treated for pneumonia 18 years ago and suffers with recurring chest infections, requiring treatment in hospital. She also has other chronic conditions, including adrenal insufficiency.

Over the past couple of years, the impact of her condition on her daily life has been severe, mentally as well as physically. Julie, who lives in Surrey, has been housebound for extended periods and struggled emotionally with the limitations imposed by her condition.

“You have to make a mental adjustment to what you are able to do,” says Julie. “You have to find your value again, which is a real challenge.” Julie says she

has had suicidal thoughts in the past but feels that she has turned a corner. Julie works for the disability charity Scope as stories officer and appreciates the profound difference of having a supportive employer.

Julie strongly recommends joining a support group to be able to talk with people who share your experiences. “It does help to know that you are not alone and you can learn from the way other people respond to challenges.”

Recommendation 3g:

Respiratory guidelines should involve positive interventions for people with mental health problems

Foundation’s Breathe Easy network can have a positive impact by encouraging social interaction with people who share similar experiences of living with lung disease, both for individuals and carers.

Measure of success:

Data need: Patient-reported experience of whether they have been supported with a mental health problem to be measured in the proposed new patient survey, with a baseline established within one year.

Respiratory illness often goes hand in hand with mental health problems.²¹ The symptoms and effects of lung disease (breathlessness, lack of mobility, isolation) can lead to anxiety and depression.

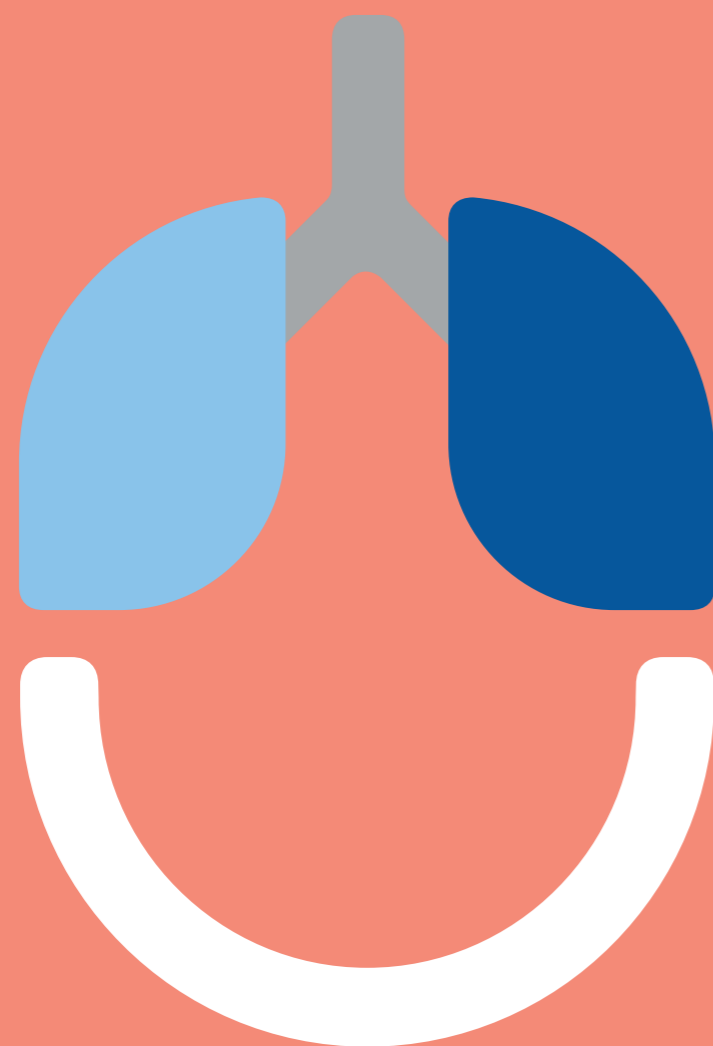
People with pre-existing mental illness are also at increased risk of lung disease, in part because smoking rates are higher for people with mental health problems.²² Yet, they are less likely than those without mental illness to get the best levels of care. People with suspected COPD who also have severe mental illness are less likely to have their COPD diagnosed through spirometry. This means many people with mental health problems will live with undiagnosed and untreated lung disease.

Having both mental health problems and lung disease substantially increases patients’ use of the NHS. People with COPD and mental health problems are more likely to be admitted to hospital and may spend twice as long in hospital as those without mental health problems.²³

All people living with lung disease, who could benefit, should be offered mental health support or coaching. This should be flagged in all treatment pathways to ensure health care professionals are aware. Patient support groups such as the British Lung

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Chapter 4: Living with a lung disease

People with lung disease want to live full and active lives and do the things that are important to them and to their families. There are many skilled professionals and fellow people living with lung disease who can make a profound difference but are frustrated by obstacles in their way. Health services are patchy and inconsistent: getting the right care can depend on where you live rather than what you need.

The system is set up to respond to crises rather than to help people stay well. Some people with lung disease spend too much time in hospital when they want to be at home, being supported in their communities among family and friends. Many people will develop lung disease, or see a worsening of their symptoms, as they become older and more frail. It is especially important that people in this situation and those who care for them, including informal carers, can get the support they need close to home.

Lung disease can have a huge impact on patients' and informal carers' quality of life, with both feeling the effect of this daily. Lung disease is recognised as a disability, but it can be difficult to assess. People with lung disease face obstacles in their daily lives which should be addressed by improving access to a range of appropriate support, from Blue Badges to subsidised mobility scooters.

The Taskforce makes recommendations that put people living with lung disease first, at the heart of care which is designed to meet their needs by responding to them as individuals.

Recommendation 4a:

Every person with lung disease to have a personalised care and support plan. Patients, families and carers should have access to relevant information about their condition, treatment and management

Many people with lung disease are left in the dark about critical aspects of their treatment and care. They feel they are not being listened to and left out of conversations about what is being planned for them. This limits the control they have over their day-to-day lives. It also affects their own ability to reduce the risk of flare-ups of symptoms and to manage them when they happen.

A personalised care and support plan is standard for patients with a number of other chronic conditions but is often not available to people with lung disease. Action plans include all the information people need to look after themselves as best they can, so they are likely to have fewer symptoms and significantly cut the risk of attacks and the need to go to hospital.

Personalised care and support plans for lung conditions should be a partnership between the person and health care professionals, produced jointly and tailored to the individual's needs. Plans should go beyond simply managing symptoms and should aim to improve quality of life and allow people to do what matters to them. Plans should be individualised, addressing a person's self-identified support needs. They

may include information on the condition, pharmacological and non-pharmacological treatments, management and, where appropriate, digital support.

The plans should be available in hard copy and online and updated when new information becomes available. People should be able to update the plans when they want and should be able to give permission for families and carers to access

the information they need. This means that plans should be flexible, and easy to alter to meet the person's needs as they change.

Measure of success:

Data need: Patient-reported experience of whether they have a personalised care and support plan to be measured in proposed new patient survey, with a baseline established within one year.

// We are using technology from two decades ago



Image © Grange Photography/RCCGP

Steve Holmes is a GP in Shepton Mallet, Somerset, who has a strong commitment to lung health. He is respiratory clinical lead for Somerset CCG and chairs the Somerset Respiratory Network.

He says that one of the main obstacles to good care of people with lung disease is the delay caused by poor communication between GPs and hospitals. This is rooted in the NHS's continued dependence on outdated paper-based systems and the failure to use the latest technology. This means Steve's patients must often wait several weeks for vital information about their health after seeing a consultant in hospital.

Steve cannot access records in hospital on behalf of his patients, nor can a hospital

consultant see patient records held at the GP surgery. This has a material impact on decisions that must be taken affecting care, particularly when a patient's condition is deteriorating. Steve says many colleagues in other parts of the country share his frustration.

Steve says: "Quite rightly, patients find it hard to understand that the health professionals responsible for the care don't all have the same information at their disposal at the same time. It doesn't happen in other walks of life.

"We've been talking about a paperless NHS since the mid-1990s and we are still a long way from that. We are using technology from two decades ago and it is affecting care."



// Understanding more about asthma helps to build my confidence

Sarah Johnson's sons Thomas, 13, and William, 3, have asthma. "On quite a few hospital visits we were told William had bronchiolitis or a viral-induced wheeze," says Sarah. On a later visit a doctor said he needed asthma medicines and put him on a preventer inhaler, reliever inhaler and a medicine to keep airways open.

Thomas was diagnosed with asthma after a year or so of getting pains in his chest, mostly after or during exercise. One day when he was 12, he had particularly bad pains in his chest when he was playing rugby and started panicking. "I took him to hospital and he had ECG tests done for his heart, but then the doctor tried him with a blue reliever inhaler and it made an almost immediate difference," says Sarah. "He used it for a while but needed it more and more often, so the doctor decided to put him on a preventer inhaler as well."

The children's asthma symptoms tend to be severe chest pains, and William's wheeze sounds like a little whistle. "I've realised that asthma is more than just struggling to breathe," says Sarah. "It is about having inflamed or sensitive airways that need to be soothed by preventer inhalers so they don't react to triggers with symptoms like wheezing and a tight chest or coughing at night.

"I wish my doctor had recommended the Asthma UK website when they were first diagnosed as knowing there are other parents out there going through similar experiences is really helpful. Understanding more about asthma helps to build my confidence when I'm helping them deal with asthma symptoms."

Looking after carers

Informal carers play a key role in supporting people with lung disease, particularly when disease is advanced. Carers, including family members and friends in a supportive role, provide physical and psychological support to enable people with lung disease to get on with daily activities such as bathing, dressing, housework and shopping. Support is often provided 24 hours a day. Carers can help in interpreting and questioning advice from health care professionals. They can play a positive role to improve adherence to treatment and provide helpful insights into a person's limitations.

The impact on carers' own physical and mental health is profound. Carers of people with lung disease report anxiety and depression, fatigue, social isolation and uncertainty. Their personal relationships suffer.

Carers need support too. Although this issue is beyond the scope of this report, the Taskforce encourages health care professionals to recognise their responsibilities to informal carers. Supporting carers will also have a positive impact on the people they care for.¹

Knowing what to ask for

The British Lung Foundation COPD Patient Passport helps people living with chronic obstructive pulmonary disease (COPD) find out whether they are receiving the care they are entitled to, and what they should do if not.

It takes 10 minutes to complete and the information provided is entirely confidential. People answer 'yes' or 'no' to a series of questions about their care. At the end they receive a personalised passport which can be shared with their doctor or nurse.

The passport has three objectives: to inform people of care that they should expect; to provide a discussion tool to use during consultations, and to develop a picture of patient experience.

The Patient Passport was developed with the Primary Care Respiratory Society and members of British Lung Foundation Breathe Easy groups. The printed passport was distributed to every GP practice in the UK.

Recommendation 4b:

Improve access to pulmonary rehabilitation so that every person with an MRC breathlessness score of grade 2 and above is identified, referred to and has the opportunity to complete, a programme

advice on managing symptoms, including feeling short of breath, nutrition and psychological support. People who smoke will also be given advice on how to stop.

A pulmonary rehabilitation team includes trained health care professionals such as physiotherapists, nutritionists, nurses and psychologists. Pulmonary rehabilitation is currently designed for people who are affected by their breathlessness and is also effective at helping people prepare for lung surgery.

Although the benefits of pulmonary rehabilitation are widely recognised, many people with lung disease are not offered it because services are not available in some parts of England. Others can find it difficult to access the services due to transport issues, or because their health means making the journey can be too difficult.

Only 15% of people with COPD at MRC grade 3 and above are referred to pulmonary rehabilitation services.²

Pulmonary rehabilitation, also known as PR, is one of the most effective interventions for people living with lung disease. It is important for health care professionals to promote its benefits to patients, which include a reduced risk of admission to hospital.

Pulmonary rehabilitation involves a physical exercise programme, tailored for each person. It includes information on looking after the body and lungs,



If everyone who would benefit from PR had access the NHS would avoid hospital admissions and free up GP appointments.

This is despite estimates that 40% of those people at MRC grade 3 and above are eligible. In addition, rates of take up and completion are poor. Of those people currently referred, only 59% start their programme and 42% complete it.³

Every person in England with a score of grade 2 on the MRC breathlessness scale (defined as 'short of breath when hurrying or walking up inclines') or above who could benefit should be identified and referred to a pulmonary rehabilitation programme. Services should be local, accessible to people, and tailored to their disease. People should be referred at an appropriate stage in their disease to maximise the benefits.

Maintaining exercise after a pulmonary rehabilitation programme is also vital, and people should have the opportunity to do this.⁴

More comprehensive data collection is needed to help plan and provide effective services in England. The Taskforce welcomes the Royal College of Physicians' Pulmonary Rehabilitation Services Accreditation Scheme (PRSAS), which recommends standards for all pulmonary rehabilitation services.

Measures of success:

Increased referral to, and completion rates for, pulmonary rehabilitation programmes for people with COPD with an MRC breathlessness score of grade 2 and above.

Increased number of pulmonary rehabilitation programmes which accept people with COPD with an MRC score of grade 2 and above.

An increase from 53% in the proportion of people with idiopathic pulmonary fibrosis (IPF) referred to a pulmonary rehabilitation programme, as measured by the BTS IPF registry, with a target established within one year.

Data need: National Asthma and COPD audit programme will start collecting data on every patient with COPD referred to pulmonary rehabilitation in England from March 2019 to establish a baseline on referrals.

A right to rehabilitation

Making pulmonary rehabilitation more widely available than it is currently has significant benefits. There would be significant financial savings for the NHS and social care, according to the Chartered Society of Physiotherapy (CSP). For example, if every eligible person with COPD in England was referred to a programme there would be 26,600 prevented hospital admissions each year.⁵



Simon Pearce has a number of lung conditions, including COPD, asthma and bronchiectasis. He first heard about the benefits of pulmonary rehabilitation in 2013 when he attended a British Lung Foundation Breathe Easy group in Darlington and was keen to learn whether he would be eligible. However, it took another three years and two moves, first to Dartford, then to Enfield, before he found a consultant willing to put him forward. "I'm not sure why, but specialists didn't want to talk to me about pulmonary rehabilitation," Simon says.

In 2017 Simon finally attended a course run by NHS physiotherapists at a leisure centre in Enfield over six weeks. "Pulmonary rehabilitation has helped

me," Simon says. "I have been able to do more, which has meant I can get out of the house more often. I still get out of breath, but I recover quicker." He says that he has learned more about how to manage his health and he has not been admitted to hospital for more than a year. Simon's GP in Enfield has suggested a second round of pulmonary rehabilitation, which he is keen to pursue. Simon says: "Pulmonary rehabilitation has definitely helped me and I recommend other people with a lung condition ask their consultant about it."



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We knew lots of people would benefit, but we couldn't reach them

Homerton University Hospital in Hackney launched an initiative to encourage more people with lung disease to take part in pulmonary rehabilitation. This followed publication of the national clinical audit of pulmonary rehabilitation services in England and Wales in February 2016. The audit showed that many people who would benefit did not enrol in PR or dropped out before completing treatment, possibly put off due to long waiting lists.

Laura Graham, Respiratory Lead Clinician at Homerton and a specialist respiratory physiotherapist, says the national audit chimed with the hospital's own experience. "The national audit was a turning point. We knew that there was a significant population who would benefit from pulmonary rehabilitation. But we could not reach them or we could not support them to complete treatment."

Homerton has introduced a number of innovations, which include a psychologist attending classes once a week, offering support around the emotional challenges of pulmonary rehabilitation and following up with people who do not attend. In addition, a multi-disciplinary team hold an education session, which everyone referred attends before their pulmonary rehabilitation assessment. This has resulted in improved attendance at the pulmonary rehabilitation assessment and completion of the course.

The hospital has also introduced a lower level breathlessness rehabilitation group for the frailer people with more complex needs being referred. This group enjoys high levels of patient satisfaction despite some challenges, including the need to provide transport. This offers choice to people who would otherwise be seen at home.

Recommendation 4c:

Expand the use of non-pharmacological treatments for breathlessness and cough

Breathlessness and cough are two of the most common symptoms of lung disease and are the most difficult for an individual and their families to manage. They can have a significant impact on quality of life.

Non-pharmacological treatments do not use drugs, can be effective and are currently underused. They include cognitive behavioural therapy, cough suppression techniques, breathing techniques, use of handheld fans, singing, exercise, pulmonary rehabilitation and nutrition.

Social prescribing programmes have the potential to link people with activities, classes and courses that can help them to manage their condition and improve their quality of life. Health coaching can also help people change their behaviour, such as increasing their activity levels.

Research is needed to identify the most effective non-pharmacological treatments to help people and families. Health care professionals are inconsistent in their use of these therapies, which means some patients are disadvantaged.

Measure of success:

Data need: Patient-reported experience of their access to and use of non-pharmacological treatments to be measured in proposed new patient survey.

Recommendation 4d:

Promote and signpost people living with lung disease, their families and carers to support groups which are run in joint leadership between people affected by lung disease and health care professionals

Living with a lung disease can be an isolating experience, leading to feelings of loneliness and increasing the risk of mental health problems. Initiatives that bring together people with a shared experience of their condition in an informal setting can have a profoundly positive impact. People are better able to manage their condition with peer support.

The most successful support groups are those formed by people with lung disease and health care professionals working together. Efforts should be made to support relatives and carers, who can become isolated.

Health services must strive to overcome barriers to setting up and running support groups, which include cost and availability of accessible premises. People who are less mobile may need transport. Online communities can help maintain contact between events and help those who cannot attend to feel included still.

Measures of success:

An increase from 43 to 80 in the number of Integrated Breathe Easy groups supported by commissioners, to be monitored by the British Lung Foundation.

An increase in the number of patients accessing an Integrated Breathe Easy group, with individual groups required to collect and report data.

An increase from 70 to 100 in the number of pulmonary fibrosis support groups, to be monitored by Action for Pulmonary Fibrosis.

Getting friendly, local support

Integrated Breathe Easy groups (IBE) provide a cost-effective way to support people living with lung disease, while bringing wider social benefits to local communities.

IBE groups are an evolution of the British Lung Foundation's successful Breathe Easy network, which has been developed over two decades. In 2014 the BLF started a project to join up Breathe Easy groups with local care pathways. The IBE model, which formally involves local commissioners and health care professionals with the activities and programmes of peer-to-peer support groups, has been independently evaluated by the Centre for Health Service Studies at the University of Kent.⁶ Key findings include a minimum return of £5.36 for every pound invested through better health outcomes; a 42% reduction in unplanned GP visits, and a 57% reduction in unplanned hospital admissions for people attending IBE groups compared to those in standard Breathe Easy groups.



If you come to a support group and put out your hand, somebody will hold it



People living with a chronic lung disease often feel lonely and isolated. Support groups are a great way to meet other people with the same disease, learn more about your disease and support each other emotionally.

Action for Pulmonary Fibrosis facilitates a network of 70 support groups across the UK. Groups are organised by health care professionals and people with lung disease and generally meet every two months. Meetings vary in size from 20 to 60 people and take place in hospitals or community and church halls. Most meetings have an outside speaker and include time for discussing and socialising. Talks may be on clinical topics, such as oxygen therapy, or a wide range of other topics.

Malcolm Mason (left), 71, had been a member of the Papworth Hospital support group for more than five years and recently joined the new Mid-Essex support group in Chelmsford. He said: "At support group meetings you meet people who are on the same journey as you and can support each other. Being told you have IPF is devastating but if you come to a support group and put out your hand, somebody will hold it. We are all here for each other." Sadly, Malcolm has died since telling his story.

Steve Jones, an IPF patient who has had a single lung transplant, says he was initially a bit scared of going to a support group, but came out with a spring in his step. "People were so warm and friendly," he says. "I learnt so much about IPF and how to live with the disease. It was really empowering."



The BLF Integrated Breathe Easy (IBE) group in Eastbourne, East Sussex, has 25–35 regular members, making it one of the most successful groups in the country.

The group's chair is Kim Cole, who lives with a long-term lung disease.

Kim says that one of the group's great strengths has been that, through the IBE model, they work very closely with NHS partners. The group is working with physiotherapists and Brighton University to develop a programme to follow on from pulmonary rehabilitation. The group also engages with a varied range of speakers, such as pharmacists, inhaler technique specialists, herbalists, physiotherapists, welfare advisers, mental health experts, stress incontinence nurses and many more.

The group, now in its third year, meets monthly. Singing is a very popular activity among members. They also have the benefit of their own allotment with raised beds, which is accessible for members with mobility problems. Once a year the group has an annual outing and a popular Christmas party. Kim says that even though the group is well-attended there are many people with a lung condition who are unable to attend regularly, including people of working age and children. The group is self-funding and raises money for the British Lung Foundation.

Kim says that co-ordinating the group is time-consuming, but the positive impact for members makes it all worthwhile. "Living with lung disease can be isolating, frightening and lonely, so members really enjoy meeting other people who understand the impact that living with a lung condition has on life."

Recommendation 4e:

Expand the delivery of NHS Medicines Use Review and NHS New Medicine Services in pharmacies and remove the cap on the number of these they can deliver

a result of people being better supported to manage their medication and general lung health.⁸

A further problem is that there is no system to notify a patient's doctor that a pharmacist has reviewed their medication. As a consequence, there is likely to be duplication of work by staff in GP practices, nurses and pharmacists. There needs to be better collection and sharing of information (see recommendation 2b in Chapter 2: Identifying lung disease early).

Measure of success:

The cap on NHS Medicines Use Reviews and NHS New Medicine Services to be lifted in one year.

Pharmacists are well-placed to check with patients that they are using medicines safely and effectively. This is a particular concern for people with lung disease who are often taking medication for more than one long-term condition. Incorrect use is also more likely to cause side effects.

This risk can be managed through better application of the Medicines Use Review (MUR) and the New Medicines Service. These evidence-based services, commissioned by the NHS and provided through pharmacies, are designed to ensure people are on the right prescriptions for their conditions and are taking medications safely.⁷

However, patient access to these services is inconsistent. There is a cap on the number of reviews pharmacies can carry out, set by the Department of Health and Social Care at 400 interventions for each pharmacy each year. This means some people are turned away and must wait several months before their pharmacist is able to provide the service.

This cap needs to be lifted to allow more people to benefit from reviews. The cost of providing more reviews in pharmacies is balanced by savings created to the NHS as

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Being able to advise patients means they are less likely to have side effects

Angela Chalmers is a community high street pharmacist in Hertfordshire. She believes that the Medicines Use Review (MUR) is an essential tool to help people manage their lung conditions. It is particularly valuable when it comes to advising people to use their inhalers, as in her experience many people do not know how to use their inhaler correctly.

"When an inhaler is prescribed, there is a lot of information given to the patient all in one go," she says. "A 15-minute appointment with the GP is not long enough to fully go through inhaler

technique and it is difficult for patients to absorb all of the information during one visit to the surgery." This is where the role of community pharmacy and a MUR is so valuable, as the pharmacist has time to talk the patient through their medicines. Being able to advise patients on correct techniques with inhalers and oral health means they are less likely to develop a sore throat or other side effects.

Community pharmacy plays a number of important roles in patient care. "As a community pharmacist, who is passionate about lung health, I am always looking for the opportunity to help patients with their medication, whether this is through counselling, MUR or supporting with self-care," Angela adds. "Improving adherence saves money for the NHS and improves patients' lives."

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Chapter 5:
The right care
in the last year
of life

For many people, lung disease will not be curable and symptoms will create increasing problems for patients' families and carers towards the end of life. Managing end of life care needs to consider these specific difficulties associated with deteriorating lungs. Advance care planning should be available to everyone with lung disease.

The unpredictable nature of many lung diseases means it is often not possible to give any certainty about how much life people have left to live. The presence of symptoms does not necessarily mean someone is close to death. They might have been part of a person's life for months or even years. Each person's experience at the end of life is different. People with lung disease tell us that what is important to them is having a realistic understanding, from those who care for them, of what they can expect in terms of possible symptoms, quality of life and disease progression.

Some people do not have access to individual support in time to make the best-informed decisions about their own death. Many people want to have a say in where they die, such as in their own home, in hospital or in a hospice. But that choice is often denied to them through the absence of planning or the limited options available in their community.

We need to make sure that the right care and support for people with lung disease and carers is available when they need it. At the end of life, breathlessness, in particular, can be a very distressing symptom to deal with both for the person with lung disease, and for family and friends supporting them. Not all health care professionals are able to confidently and competently offer support.

NHS England has endorsed the National Palliative and End of Life Care Partnership's framework for delivering end of life and palliative care. We have used these principles to make recommendations for people with lung disease.

Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020

1. Each person is seen as an individual

I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible.

2. Each person gets fair access to care

I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.

3. Maximising comfort and wellbeing

My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.

4. Care is coordinated

I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.

5. All staff are prepared to care

Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.

6. Each community is prepared to help

I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.

Recommendation 5a:

Every person with lung disease and their carer(s) should have access to a shared decision-making programme where they can identify areas where they need additional support

Planning for end of life should begin early and be revisited throughout illness because lung disease is not always predictable.

The shared decision-making programme can identify when support with end of life care might be needed and the programme could be shared between health care professionals. Holistic support must be offered to people with lung disease and extend to carers and family members to help them understand and manage the physical and emotional toll of looking after a person with life-limiting or terminal lung disease.

Will contribute to:

Each person being seen as an individual, maximising comfort and wellbeing, and with health care professionals working in partnership to achieve a patient's wishes.

Measure of success:

An increase in the number of people with lung disease who have a personalised care and support plan in the last year of life.

Data need: NHS England to collect data on the proportion of people with lung disease who are identified as approaching the end of life and have shared personalised care and support plans.

Recommendation 5b:

People with lung disease should be supported to stay at home where appropriate

Many people want to be cared for at home in familiar surroundings. This may not always be achievable, but it is important for individuals and their families to be involved in conversations about end of life care.

People with lung disease should be able to expect good end of life care at home, wherever feasible. Community care nurses can provide or arrange hands-on nursing or personal care, advise on pain and symptom control, and provide practical and emotional support for the patient and carers at home. When required, social services or local community teams must provide the services and equipment needed to help people remain at home if that is their wish, including home adaptations such as hospital-type beds.

Will contribute to:

Maximising comfort and wellbeing, with each person seen as an individual.

Measure of success:

An increase in the average proportion of time people with lung disease spend at home in the last year and the last 90 days of their life.

Data need: NHS England to collect data retrospectively on the proportion of time people with lung disease spend at home, in hospital or elsewhere in their final year of life.

Starting a conversation

Patients rarely have enough time with health care professionals and, even when there is time to talk, people can be uncertain what they can ask about.^{1,2} Health care professionals cannot rely on people telling them their concerns and may be reluctant to ask or be preoccupied with immediate medical issues. This can make planning good end of life care difficult.

The Support Needs Approach for Patients (SNAP) is an intervention developed by the University of East Anglia and University of Cambridge that enables person-centred identification and response to patients' unmet support needs. The intervention is underpinned by a tool with 15 evidence-based questions for people to help them to consider areas where they need more support. People complete the SNAP tool then have a needs-led conversation with a health care professional to express, prioritise and address the unmet support needs identified.

Hospital care at home

Royal Brompton Hospital, London, launched an initiative called Hospital2Home (H2H) to support patients' end of life care choices, aimed particularly at those affected by advanced interstitial lung diseases (ILDs).

The aim of H2H is to aid the transition of care for people from hospital-based treatment to care nearer to home. H2H gives patients and their families and friends more confidence about making the choice to be cared for at home by improving communication between hospital and community services.

Through the H2H scheme, every member of the health care team who has a legitimate relationship with a patient will have easy access to information about their end of life choices, no matter where they are based, ensuring a seamless and improved service for the person.

A study of H2H, involving 53 people, suggests that community case conferences improve easing of symptoms and quality of life after four weeks.³



Divya Malde's mother, Lalita, died last year at the age of 82. She was diagnosed with idiopathic pulmonary fibrosis (IPF) in the summer of 2008, and in 2014 she was diagnosed with Alzheimer's. Despite her illnesses she was initially very determined and lived with a degree of independence, latterly supported by family and carers. As she neared the end of her life, Divya and her family decided to arrange for Lalita to remain in her home in Kettering rather than spend her final days in a hospice.

"I wanted to have a conversation with my mother but she did not want to discuss death and it was too emotional," says Divya. "But mum would not have liked to be in hospital or in a hospice. She passed away in familiar surroundings, which is what she would have wanted."

Divya's sister is a GP and had knowledge of the care system.

"This made a big difference to the family because it helped us to arrange the care and equipment mum needed at home," says Divya. "It is more difficult for families who don't have that experience, and particularly for those people who are alone."

Having an experienced carer to support the family at home also made a profound difference, Divya says. "She was so comforting, talking, holding hands with mum. She knew precisely what to do and say when the time came."

"If your wish is to die at home, it is possible to make arrangements to enable you to do so. You will need the support of your family, carers and medical professionals. You must tell these people of your wish early on."

Recommendation 5c:

Health care professionals should be aware of the range of therapies that can help with and mitigate breathlessness, pain, depression and anxiety at the end of life

Helping people manage breathlessness, coughing, pain, depression and anxiety at the end of life is a significant challenge for health care professionals. This aspect of care should form part of training to improve awareness of the range of therapies available.

Non-pharmacological strategies, including breathing techniques, use of handheld fans and emotional support, are often effective, inexpensive and relatively simple to carry out. Care should be tailored to individual need in collaboration with the person and their carers.

People with chronic lung disease, such as COPD and ILD, often experience as much pain and as many mental health problems as people with cancer, but these symptoms are not always addressed in people with long-term conditions. As well as supporting people to manage breathlessness, health care professionals should also support them to manage less obvious, but no less debilitating, symptoms such as depression and anxiety.

Will contribute to:

Maximising comfort and wellbeing, with each person seen as an individual.

Measure of success:

Data need: Patient-reported experience of access to and use of therapies to mitigate breathlessness and other symptoms to be measured in proposed new patient survey, with a baseline established within one year.

Recommendation 5d:

Generalist and specialist respiratory and end of life services should work together to deliver end of life care

There is strong evidence that people with lung disease are much less likely than other patients approaching end of life to be offered care that is tailored to their individual needs.⁴ One of the reasons for this is that lung disease can be unpredictable, and symptoms are inconsistent, so it is difficult to know when end of life is nearing. This means that conversations about end of life care often do not happen early enough to allow people to influence decisions that will be made at a later stage.

This is made worse by the fact that respiratory specialist services and services to help people towards the end of life are run separately. There is a strong case for an integrated breathlessness support service including respiratory medicine, palliative care, physiotherapy, and occupational therapy for people with advanced conditions and breathlessness at rest. Joint clinics

between specialist palliative services and respiratory teams would be an important step towards embedding joint working.

Will contribute to:

Each person gets fair access to care, maximising comfort and wellbeing.

Measure of success:

Patient-reported experience of whether they have received joined up, appropriate care to be measured in proposed new patient survey, with a baseline established within one year.

Bringing specialists together

New Cross Hospital in Wolverhampton has had a joint palliative and respiratory clinic since June 2015. Referrals are usually made by the chronic respiratory multi-disciplinary team or after discussion with the respiratory consultant or palliative care consultant. The main objectives are to provide coordinated respiratory and palliative care, and to improve patient understanding about diagnosis and outcomes. These are achieved through joint discussion around the person's main symptoms and improving understanding of disease and future progression and treatment options.

The clinic has made it possible for people with end stage respiratory disease to have coordinated and integrated access to palliative care and respiratory services. To date 66 patients have attended the clinic, of whom 30 have subsequently died. Only two of those who died passed away in hospital, which was not their stated choice. The others died at home or in a hospice. Significantly fewer people reported being anxious or worried about illness and treatment after coming to the joint clinic.

No additional funding was required for the joint clinic as both consultants had clinic time within their job plans.



St Christopher's Hospice, based in Sydenham, South East London, introduced a breathlessness management service three years ago. This is an outpatient service, led by a physiotherapist, an occupational therapist and a cognitive behavioural therapy (CBT) therapist, to support people with chronic lung conditions by teaching strategies to cope with breathlessness better.

It uses the Breathing, Functioning, Thinking model developed by Addenbrooke's Hospital in Cambridge. The service includes an individual assessment with a therapist, followed by three weekly small group sessions. Week one focuses on posture, breathing techniques at rest and strategies to manage acute breathlessness. The second week is about function and movement, including gentle seated

exercises and pacing advice. Week three considers unhelpful thoughts associated with breathlessness and ways to manage anxiety and panic, including CBT techniques and mindfulness. The service is for carers as well as patients.

Kate Norman, physiotherapist at St Christopher's, says: "Breathlessness can be a frightening and restricting symptom that many people with life-limiting illness experience. We help them to understand this symptom and empower them by teaching strategies to cope with it more effectively. This is often evidenced by an improvement qualitatively in chronic respiratory questionnaire (CRQ) scores, increased confidence with activity and reduced anxiety associated with breathlessness."

Facing the end of life with good advice and care

North Manchester Macmillan Palliative Care Support Service is a partnership between the CCG, the hospital trust, Macmillan and a local hospice. Across a wide geographical area with limited palliative and end of life care services, it aims to enable people to end their life in the place of their choice.

Key to this has been educating GPs and other frontline staff to be able to identify people approaching the end of life and refer them to the specialist service. The partnership provides training opportunities for health care professionals to do this.

There's a 24/7 helpline for patients and carers so that they can access advice and support whenever they need it, which offers a huge amount of reassurance. A multi-disciplinary team meets daily to consider the needs of the people being supported by the service and ensure they are being met.

The service has been successful in identifying people nearing the end of life and providing them with tailored support. There has been a 90% increase in the number of patients on GP palliative care registers and a reduction in unplanned hospital admissions for people using the service.

Recommendation 5e:

All health care professionals should be able to offer basic end of life care advice

Basic end of life care advice should be embedded in training programmes for all care staff. This will make it easier for individuals and their families to have access to care that is tailored to their needs and wishes as their disease progresses.

Local Education and Training Boards (LETBs) and in the future Community Education Provider Networks (CEPNs) should work collaboratively with commissioners, providers and other partners to deliver effective workforce planning for end of life care. This will collectively identify future staffing skills requirements (such as advance care planning, communication skills, shared decision-making, and use of coordination systems), values and behaviours, as well as numbers of staff. An assessment of end of life training needs should be made across local health and care systems. There should be opportunities for continuing professional development for health care staff and volunteers involved in end of life care.

Will contribute to:

Care is coordinated, all staff are prepared to care, each community is prepared to help.

Measure of success:

An increase in the number of health care professionals who have completed training in end of life care.

Data need: Data to be collected by Health Education England on the number of health care professionals who have accessed and completed training in end of life care, with a baseline to be established within one year.

GPs have a central role

The Royal College of General Practitioners (RCGP) recognises that GPs have an essential role in helping people die with dignity, providing individualised care and minimising distress. GPs are trained to provide personalised plans for the care of patients approaching the end of their lives, including provision for someone who is terminally ill to choose to die at home if they wish. The RCGP recognises that team work, cooperation across agencies and communication are fundamental to good end of life care. To support general practice staff in end of life care, RCGP and Marie Curie have recently published new Daffodil Standards that will be rolled out from late 2018.⁵

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Chapter 6:
**A workforce
for the future**

We have a dedicated and talented workforce ready to deliver this plan. But they are unevenly represented around the country, leading to different standards of treatment. This includes delayed or inaccurate diagnosis, late test results, patchy access to treatment and poor support at all stages including end of life.

We need a focus on providing integrated care for patients, delivered by staff who are encouraged to work together to provide the best care for individuals. Where appropriate, this means people with lung disease are supported by multi-disciplinary teams of staff who meet their needs. This chapter covers some of the professions involved in caring for people with lung disease, and it's likely there are insufficient numbers across other relevant staff teams.

NHS England must take a leading role. It has a comprehensive overview of which staff are needed to deliver future plans, where multi-disciplinary teams are needed to care for patients, and how they can deliver excellent care for people with lung disease. We would like to see a clear plan developed for the respiratory workforce as soon as is practicable, with time limited milestones to measure progress.

Recommendation 6a:

NHS England to provide a vision of required health care professionals for a developed workforce for quality provision of respiratory care to Health Education England by 2020, with evidence of progress towards achieving this within five years

Recommendation 6b:

Expand the NHS England drive to ensure that as many health care professionals as possible work at the highest end of their remit, for example advanced clinical practitioners and assistant practitioners

GPs

GPs are usually the first point of contact for people concerned about their breathlessness, cough or other respiratory symptoms. If there is not enough GP time available, people with worrying symptoms will find it hard to get a timely appointment and are unlikely to be able to fully explore diagnostic or treatment options.

The Five Year Forward View recommended that we need 5,000 more GPs to keep up with current demand. However, recruitment has been slow and we are unlikely to meet this target, as there is currently a net loss of GPs due to retirement. A Royal College of GPs report highlights 71% of practices are finding it hard to recruit GPs.¹

People need enough time from their primary care professionals to properly explain their condition and its management and they much prefer to have continuity of care with the same doctor or nurse so far as possible.

Recommendation 6c:

NHS England and Health Education England to refresh GP strategy with a focus on retention as well as recruitment

Respiratory consultants

There is a clear need to increase the number of respiratory consultants if lung health is going to have a higher priority in the health service. This in turn will create a heavier workload for already struggling specialities as more tests are ordered and more patients enter pathways for management and support with their lung condition.

There are high numbers of vacant respiratory consultant posts. Of those trusts that responded to a survey, 40% had at least one vacancy at consultant level and more than half reported recruitment difficulties.² Respiratory medicine is a core speciality that underpins the acute care model. However, not enough trainees choose acute medicine as a speciality area. This is compounded by the fact that new trainees will take at least nine years before they reach consultant level.

Recommendation 6d:

Create an additional 100 respiratory speciality training posts over five years (20 per year)



Lisa Davies is a consultant in respiratory medicine at Aintree University Hospital in Liverpool, which has one of the largest respiratory services in the UK. She is also Chair of the Board of Trustees of the British Thoracic Society (BTS).

Lisa says the demand for care for lung disease is high and growing. Respiratory illness is the major contributor to the increased work the NHS experiences in winter months.

Respiratory medicine is the third biggest specialty in the UK, but consultant numbers have remained constant at around 1,200 over the past 10 years. Expansion is needed and this requires an increase in the numbers of training posts.

“There are not enough trained respiratory specialists to fill current vacancies and it is

not unusual for consultant job adverts to attract only one or two applications,” says Lisa. “In fact, sometimes no one applies.

“In a recent BTS survey, around 40% of departments who replied had at least one consultant vacancy. This leads to increased workload for those who are in the department, an over-reliance on locums and the risk of sub-optimal patient care.

“We are encouraging more trainee doctors to consider specialising in respiratory medicine and need to work with them to design jobs and work patterns that are appealing and sustainable. Retention is as important as recruitment.”

Nurses

Nurses play a role at all stages of the patient journey, from delivering smoking cessation support and flu jabs to leading, coordinating and providing care at the end of life. Specialist nurses can play a key role in supporting people with lung disease, using their experience to provide high-quality care. Many of these nurses will be practising autonomously at an advanced level.³

Under new education standards being introduced, all registered nurses will be expected to demonstrate a higher level of respiratory skills and knowledge.⁴ Recent changes to nurse training funding have removed the provision of bursaries and there has also been a reduction in continuing professional development.

In addition, there is a serious crisis in staffing levels on the horizon, with almost half (44%) of nurses set to reach retirement age within 10 years.⁵

Recommendation 6e:

NHS England and the government must focus on recruitment and retention of nurses, including reviewing the funding mechanisms for training and continuing professional development programmes

Imaging specialists

Radiologists play a vital role in diagnosing and managing lung disease by carrying out imaging and interpreting scans.

More than 10% of radiology consultant posts are currently vacant. Only 3% of radiology departments report completing all work within normal hours, which risks interpretation being rushed, delayed or inaccurate.⁶

The Care Quality Commission (CQC) has reported significant variation in reporting times across the country, ranging from 24 hours for inpatients to three weeks for routine scans. There are no national standards for how quickly different types of scans should be reported.⁷

Accurate and speedy diagnosis of lung disease also relies on having enough radiologists with expertise in thoracic radiology interpretation. This should be available to all patients but currently specialism is patchy.

The success of a new national lung cancer screening programme depends on having enough capacity to analyse the CT scans that take place.

There are no consistent targets for scan and X-ray results

The time it takes to get results back varies widely round the country:

- Urgent or fast track – from two days to five working days
- Routine – from seven days to three weeks
- Emergency department – from one hour to two working days
- Inpatient – from 24 hours to 60% of reports within 72 hours
- Outpatient – from five days to an informal KPI of 90% within 21 days
- GP/direct access – from 95% of reports within 24 hours to an informal KPI of 90% within 21 days



Recommendation 6f:

The Royal College of Radiologists, supported by the British Society for Thoracic Imaging, to introduce national standards for speed of reporting

Recommendation 6g:

Invest in sufficient workforce and equipment to ensure all departments are reporting at the speed of the fastest

Recommendation 6h:

Create regional thoracic imaging networks to share expertise between hospitals



New models of care

Homerton University Hospital is located in Hackney, one of the most diverse London boroughs. The population has a high incidence of lung disease, with high rates of smoking.

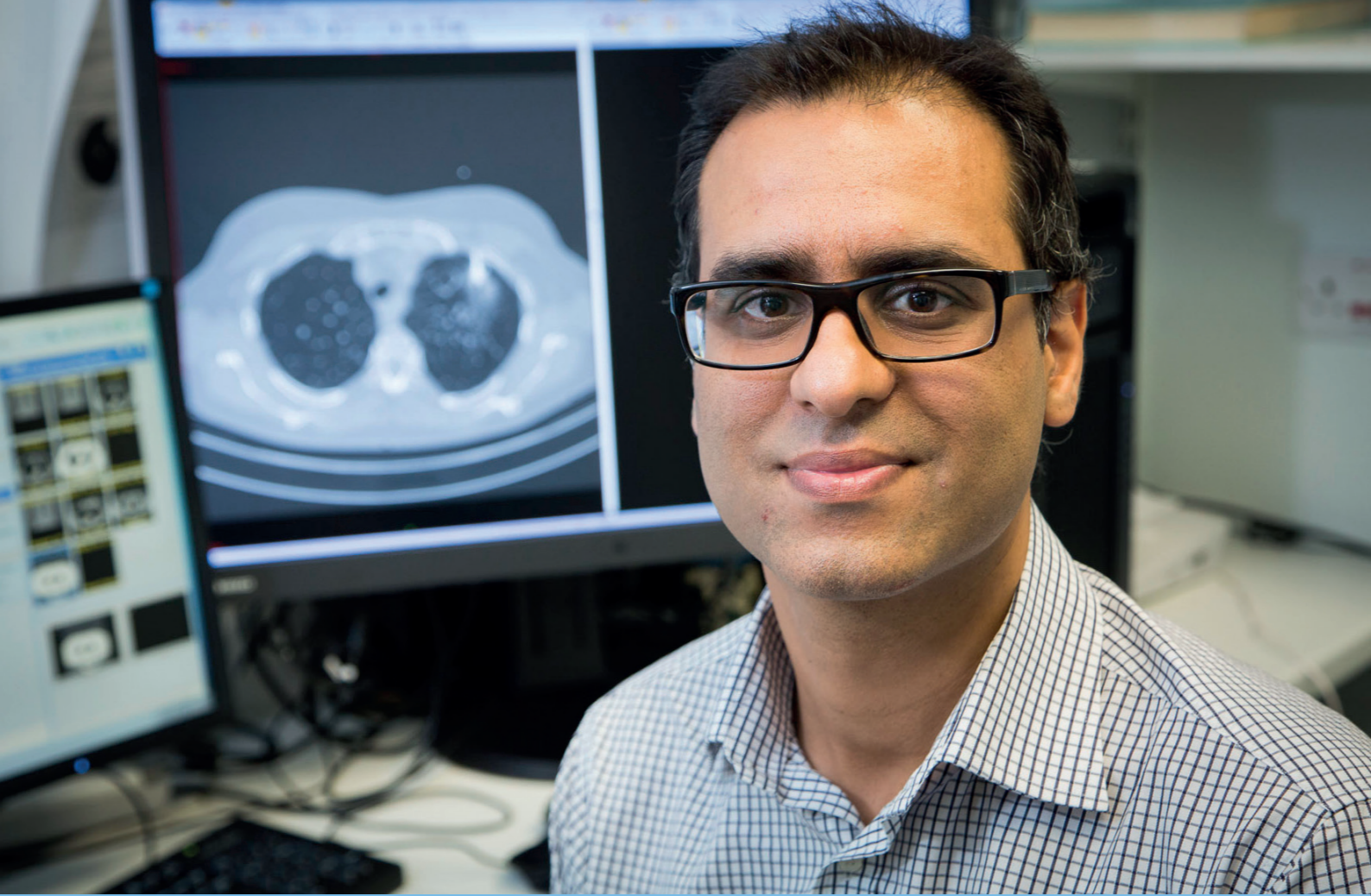
The local clinical commissioning group has made a strong commitment to lung health, supporting a team of about 25 health care professionals in the Adult Cardiorespiratory Enhanced and Responsive Service (ACERS). There are about 10 outpatient clinics a week covering the different specialist areas, where experts in their various fields consult with people on their particular health issues. They are an integrated service and work closely with the respiratory ward, a 28-bed unit, with four side rooms for particular types of illness.

ACERS includes a hospital at home service to support people to remain at home during an exacerbation and an early supported discharge service.

Debbie Roots, Cardiorespiratory Nurse Consultant, says that having a comprehensive service in place makes a significant contribution to the community. "Our work has made an impact on hospital admissions, which is good for patients but also helps the hospital.

"Our approach is quite innovative and over time we have added pulmonary rehabilitation and an oxygen service, and incorporated a heart failure service. We also now have two psychologists to support people with lung conditions.

"Our experience at Homerton shows the benefits of investment in people with the skills to help people live with the challenge of a lung condition. It is about reaching out to the community, understanding their need and building a service with the capacity to support them."



Sam Hare, a consultant thoracic radiologist and lead for chest radiology at the Royal Free London NHS Trust, says that the recruitment of more clinical radiologists must be a priority, with a particular focus on chest radiologists to improve the nation's lung health. "In 2017 there was a shortfall of approximately 1,000 full time radiologists in the UK," says Sam. "Over the next five years that is forecast to increase to 1,610 – it's vital that this supply and demand gap is addressed."

There is broad support for a national lung cancer screening programme for those people who are at high risk, but it will require a significant commitment to the radiology workforce. The appointment of respiratory physicians needs to be accompanied by investment in support services. "It is one thing to have a CT scan

performed, but only when it is accurately reported by a radiologist does it really become meaningful."

At present reporting delays may mean that many patient CT scans are unreported by the time their clinic visits come around. Often, this results in under-resourced radiology departments producing quick, provisional scan reviews and reports which may subsequently be shown to be inaccurate, causing distress to patients. Sam says: "It takes five to six years to train a chest radiologist, so decisions have to be taken now if we really are committed to accurate diagnosis and improving care."

Physiology

Respiratory physiology departments carry out a range of tests which are vital for diagnosis, such as spirometry. There are a high number of respiratory services running on a limited physiology workforce. 16 per cent have only one qualified specialist, and 69% have fewer than four. This can risk delays for patients, especially if staff are sick or on leave. A third of services report breaching waiting time targets for performing tests.⁸

Recommendation 6i:

500 additional training places to be made available by Health Education England, and delivered by the National School for Healthcare Science, to fill the current gap in the respiratory and sleep physiology/health care scientist workforce, with commissioners and providers being aware that business cases for new respiratory consultants should include the need for greater respiratory and sleep physiology/health care science workforce capacity to support them

Physiotherapists

From emergency admissions and intensive care to disease-specific services for children or adults, physiotherapists play a critical role in the treatment and management of people with lung disease across the clinical pathway.

In partnership with other health care professionals, physiotherapists deliver pulmonary rehabilitation, one of the most clinically- and cost-effective treatments for lung disease. Increasing the number of people taking part in pulmonary rehabilitation courses will put pressure on the current workforce.

In order to meet current demand for pulmonary rehabilitation, around 1,000 additional staff are needed. This includes 600 physiotherapists and other registered staff, and 400 support staff. However, as more people are referred by widening the eligibility criteria and raising awareness among doctors, more staff will be needed.⁹

NHS trusts also need to budget for existing and new staff to be trained to meet the criteria for the Pulmonary Rehabilitation Services Accreditation Scheme.

Growing numbers of university places and training courses for physiotherapists are being made available, meaning we are likely to see an increase in the current workforce to help us meet this demand. However, changes to the structure of the workforce may be necessary to ensure all people who can benefit from pulmonary rehabilitation can access the service.

Recommendation 6j:

Continue to increase physiotherapy training places to meet target of at least 600 additional physiotherapists over five years

Recommendation 6k:

Where appropriate, commission joint community rehabilitation services (for instance linking with cardiac rehabilitation) to support patients with co-morbidities while making best use of the workforce

Pharmacists

Pharmacists play a significant role in supporting patients in the community, in GP practices and in secondary care. As well as supplying medication, they can offer smoking cessation advice, give flu jabs and help people to monitor and manage their condition.

Ensuring there are enough pharmacists in all settings will help to give people the most appropriate help and reduce pressure elsewhere in the health service.

NHS England's target is for there to be 2,000 pharmacists based in general practice by 2020–2021. Although progress is being made, there were still only 708 in 2018.¹⁰ More should be done to promote respiratory as a specialism to hospital and integrated care pharmacists.

Consultant pharmacists are able to prescribe independently and can also run their own clinics. However, there are currently only 80 consultant pharmacists working across the country and they are usually employed at the discretion of hospital trusts rather than as part of wider workforce planning.¹¹ The Chief Pharmaceutical Officer recommends the recruitment of 10 times as many to meet patient need.¹²

Recommendation 6l:

Provide more training places for pharmacists in GP practices

Recommendation 6m:

Include consultant pharmacist posts in strategic workforce plans

Pharmacists play a critical role in lung health

Anna Murphy is one of just four consultant respiratory pharmacists in England and Wales. She has been in her accredited post at University Hospitals of Leicester since 2008.

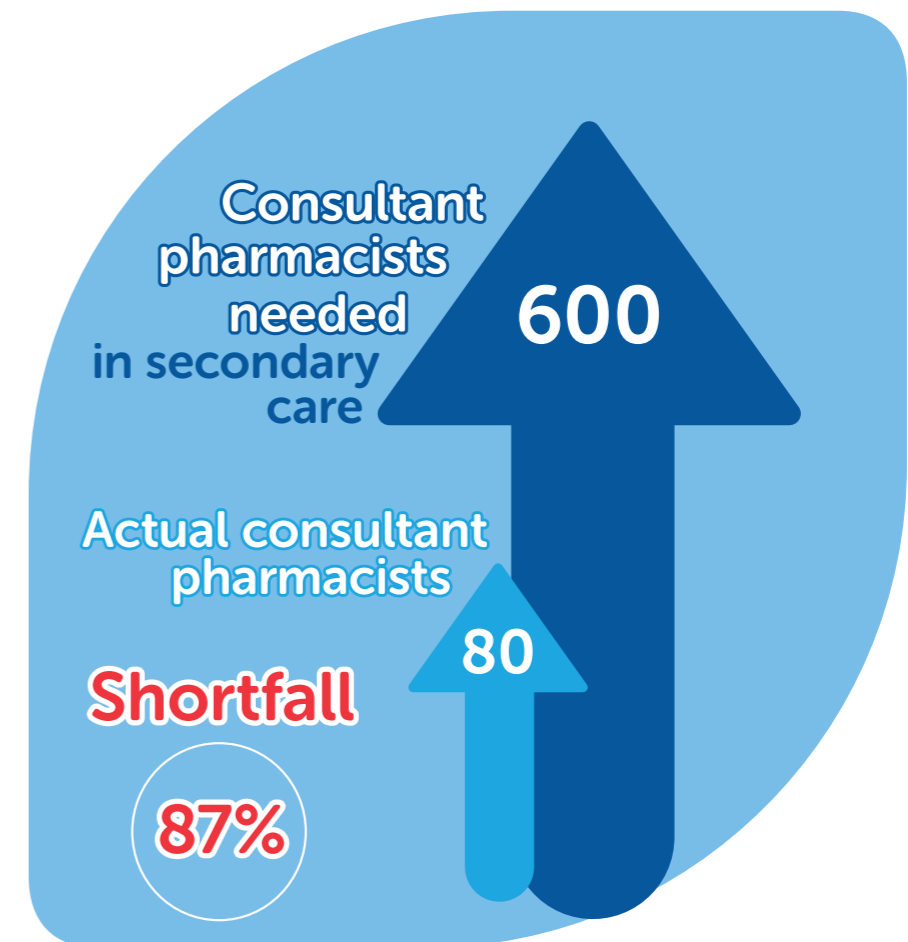
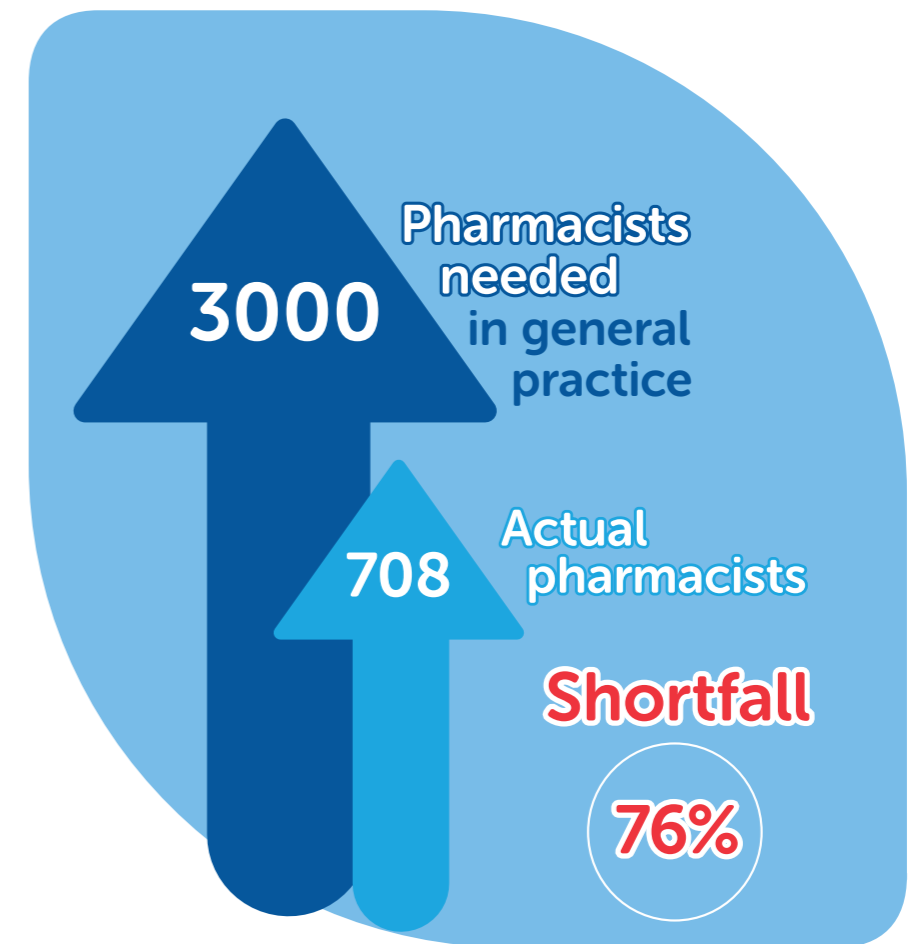
The clinical aspect of Anna's post offers assessment, medicines optimisation, monitoring and advice to people with respiratory disease, working both in hospital and primary care.

Working across Leicestershire, her post includes education and training and the development of services for people living with lung conditions.

"Gradually more pharmacists are specialising in respiratory medicine," says Anna. "The specialisation is becoming more recognised but further work is required to encourage trusts and CCGs to create posts for

specialist respiratory pharmacists. It is still unusual for trusts to appoint a consultant respiratory pharmacist. Pharmacy plays a critical role in caring for lung health, from helping people to stop smoking to supporting people to manage lung disease and live their lives as fully as possible. As a consultant, I also have the opportunity to help develop how we provide care in hospital and in the community to improve outcomes.

"It is important for patients to see that respiratory pharmacy is recognised in the same way as other specialisations", says Anna. "It also provides a pathway for career development for pharmacists looking to specialise."



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How we developed this report

The Taskforce for Lung Health was set up to develop a five year plan for improving lung health in England. It also aims to raise public awareness and understanding of lung health.

The Taskforce is independent of government. It brings together representatives from 29 organisations, representing people living with lung disease, health care professionals, the voluntary sector and professional associations. A full list of members can be found at the back of this report. The Taskforce, chaired by Alison Cook, Director of Policy and Communications at the British Lung Foundation, met throughout 2018.

This is the first time that the lung health community has come together to produce a plan to bring about the transformation that we desperately need. The size of the task facing us is too great for any single organisation to hope to achieve alone.

Our work began with a call for evidence, including examples of policy and practice which could improve outcomes for people living with lung disease if introduced or replicated across the country over the next five years.

We received 79 submissions, including 31 submissions from individuals and 48 from organisations, including voluntary organisations, industry groups, government bodies and clinical or research groups. We asked an economics agency to examine and rank the evidence submitted. Some additional research was conducted to determine background information on

certain interventions, such as patient population and value for money.

We also ran a call for evidence asking for experiences of people living with lung disease, their families and carers. We received 120 of these submissions, and the themes emerging were explored further in a workshop attended by patients and carers. These real-life experiences informed the content of the report. A number of participants are featured as case studies, along with stories from other people with lung disease. Some case study names have been changed.

The Taskforce considered the submitted evidence through a series of workshops with experts in all aspects of lung health and including patient representatives. This report presents the Taskforce's findings and makes recommendations to modernise a system that has seen little change in more than 20 years.

Glossary

Acute care: Short-term treatment, usually in a hospital, for any kind of illness or injury.

Ambulatory lung biopsy: Faster (ordinarily under one hour) radiology-led lung biopsy performed on outpatients.

Antifibrotic drugs: Drugs that block, prevent or slow fibrosis or scarring. Used to treat types of pulmonary fibrosis.

Breathe Easy groups: British Lung Foundation support groups run by and for people living with a lung condition.

Breathlessness:

- Acute breathlessness causes you to feel short of breath suddenly and unexpectedly for a short time. It usually needs to be tested or treated straight away.
- Chronic (or long-term) breathlessness leaves people out of breath every day when they are not physically exerting themselves. It develops gradually and lasts for weeks, months or years. Sometimes people also cough, bring up phlegm or feel wheezy.

Breathlessness pathway: The whole range of services for people with symptoms of long-term breathlessness, cough or persistent chest infection, including primary care, diagnosis, and rehabilitation. An integrated care pathway aims to make the journey from service to service as smooth as possible for the patient.

Bronchitis: Condition in which the airways are inflamed and narrowed, and produce more phlegm than usual, causing coughing.

It can be acute – a temporary inflammation of the airways – and chronic, or long-term, characterised by daily coughing producing phlegm.

Clean air: Air that is free of any substance that harms our health, such as tobacco smoke, gases such as nitrogen dioxide and particulate matter, including soot.

Clinical commissioning group (CCG): Organisation responsible for planning and commissioning most hospital and community NHS services, excluding primary care, for a particular geographical area.

COPD (chronic obstructive pulmonary disease): Group of lung conditions that cause obstructions in airflow that interferes with normal breathing. It includes emphysema and chronic bronchitis.

Computerised tomography (CT) scan: A scan that uses X-rays and a computer to create detailed images of the inside of the body. A CT scan is carried out in hospital by specially trained operators.

Cystic fibrosis transmembrane conductance regulator (CFTR) modulators: Drugs which modify the behaviour of the CFTR gene so that it is able to control the movement of water throughout the body.

End of life care: This care supports people who are in the last months of their life. End of life care should help people to live as well as possible until they die and to die with dignity. The health and social care professionals providing the care should ask about the individual's wishes, and take them into account.

Emphysema: Condition in which the air sacs of the lungs are damaged and enlarged, causing breathlessness.

Exception reporting: Enables clinical practices to adjust for patient-specific clinical circumstances or other reasons beyond their control (for example, where medication cannot be prescribed due to a contra-indication or side effects, where patients do not attend for review or where secondary care services are not available).

General practice: The work of health professionals, including: GPs; advanced nurse practitioners, who can prescribe and diagnose; practice nurses; and pharmacists, who are based in the community. They manage most of the minor and long-term illness in the local population and refer patients with suspected complicated problems or those who need more specialist care.

Idiopathic pulmonary fibrosis (IPF): see pulmonary fibrosis.

Informal carer: Lay person, such as a family member, friend or neighbour, in a close supportive role who shares the illness experience of the patient and who undertakes vital care work and emotion management.

Inpatient: Patient who is admitted to a hospital for treatment or an operation.

Interstitial lung disease: Group of diseases that affect the interstitium (the tissue and space around the air sacs of the lungs), causing scarring or inflammation in the lungs.

Integrated care: Care which is coordinated around the patient, making sure all parts

of the NHS and social services work more closely and effectively together.

Long-term condition: Medical condition that cannot be cured, but can be managed by treatment such as medication and other therapies. Examples include asthma, COPD, dementia, diabetes, heart disease and interstitial lung disease.

Lung disease: Any problem in the lungs that prevents the lungs from working properly. There are three main types: airway diseases, lung tissue diseases and lung circulation diseases.

MRC breathlessness (dyspnoea) scale: The Medical Research Council (MRC) scale to measure respiratory disability. It has five grades to measure degrees of breathlessness related to activities.

Models of care: Delivery model that defines the way that care would be delivered.

Monoclonal antibodies (mAbs): A new treatment for severe asthma. They are targeted medicines that work by blocking the activity of some of the immune system chemicals that trigger inflammation in airways.

Multi-disciplinary team (MDT): Groups of professionals from primary, secondary, community, social care and mental health services who work together to plan a patient's care.

NHS England: Body which oversees the budget, planning, delivery and day-to-day operation of the NHS in England as set out in the Health and Social Care Act 2012. It holds the contracts for primary care services and specialised services.

NICE: The National Institute for Health and Care Excellence which provides national guidance and advice to improve health and social care.

Occupational lung disease: Range of life-threatening or life-changing diseases that are caused by exposure to hazardous workplace agents or substances. It includes conditions that may develop in a relatively short time after first exposure and those that may develop many years after first exposure. The latter includes chronic obstructive pulmonary disease (COPD).

Outpatient: Patient who attends an appointment to receive diagnostics or treatment without needing to be admitted to hospital (unlike an inpatient). Outpatient care can be provided by hospitals, GPs and community providers and is often used to follow up after treatment or to assess for further treatment.

Oxygen:

- Ambulatory oxygen is prescribed for patients on long-term oxygen therapy who need to be away from home on a regular basis. Patients who are not on long-term oxygen therapy can be considered for ambulatory oxygen therapy if there is evidence of exercise-induced oxygen desaturation and of improvement in blood oxygen saturation and exercise capacity with oxygen.
- Long-term oxygen therapy: Long-term oxygen therapy means someone needs to use to use oxygen for at least 15 hours daily.

Palliative care: Palliative care is the active holistic care of people with advanced progressive illness. Management of pain

and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is the best quality of life for patients and their families.

Primary care: Services which are the main or first point of contact for the patient, usually GPs, nurses, pharmacists or opticians.

Provider: Individual or organisation that gives a service in return for payment.

Pulmonary fibrosis: Condition in which the lungs become scarred and breathing becomes increasingly difficult. When the cause is not known, it is called idiopathic pulmonary fibrosis (IPF).

Pulmonary fibrosis support groups: Groups run by and for people living with ILD and their carers. These groups are generally supported by national charities.

QALY (quality-adjusted life year): A measure of the state of health of a person or group in which the benefits, in terms of length of life, are adjusted to reflect the quality of life. One QALY is equal to one year of life in perfect health.

QOF (quality and outcomes framework): Part of the General Medical Services (GMS) contract to pay general practices for achieving certain objectives that improve quality of care.

Respiratory workforce: Includes all health care professionals involved in the care of lung health.

Screening: Testing of people for early stages of a disease before they have any symptoms. Currently there is no screening programme for lung cancer in the UK.

Secondary care: Hospital or specialist care that a patient is referred to by their GP or other primary care provider.

Specialist care: Hospital or expert care that a patient is referred to by their GP or other primary care provider.

Stop smoking service: Also known as smoking cessation service. Local service, developed by experts and ex-smokers, and delivered by professionals. The service provides advice and support to help people stop smoking for good. It offers free one-to-one support along with stop smoking medicines.

Urgent and emergency care: Surgery or medical treatment that is not planned and is needed urgently. It is also known as non-elective surgery.

Tobacco dependence: Addiction to tobacco products caused by nicotine. Tobacco dependence means it is difficult to stop using nicotine even though it is causing harm. Nicotine produces physical and mood-altering effects in your brain that are temporarily pleasing.

Very brief advice (VBA): Systematic advice to smokers, designed to take no more than 30 seconds, based on the ask, advise, act (AAA) model.

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