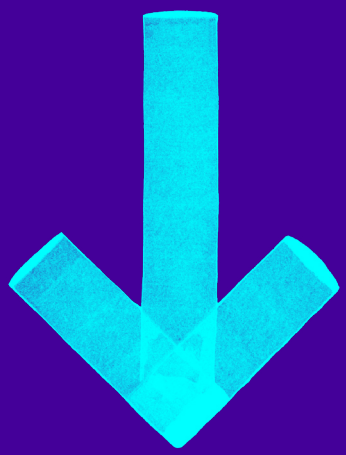
Fixing lung health in the UK

10 priorities to accelerate respiratory research and innovation.

ASTHMA+ LUNG UK

May 2024

Lung conditions receive just 2.5% of public research funding.




No one
should
be left
struggling
to breathe.

Contents

1 in 5[1] of us will develop a lung condition in our lifetime, and lung conditions remain the third leading cause of death in the UK.[2]

Yet despite lung conditions affecting so many of us, investment into respiratory research and innovation remains chronically underfunded, receiving only 2.5%[3] of public research funding.

The Lung Research and Innovation Group is a national group of patient advocacy charities, expert organisations and leading researchers determined to drive progress in respiratory research and innovation. Together, we have identified 10 priorities to ensure progress in research and innovation so that everyone living with a lung condition can live fuller, healthier lives.

We need the government and key stakeholders, including funders of research and innovation, to take much needed action on these 10 priorities.

Our 10 priorities for lung health research and innovation:

1

Promote the urgent need to progress respiratory research and innovation.

2

Identify and communicate top-level research goals.

3

Create a platform for lung health research (linking data and cohorts).

4

Urgently develop better diagnostic and monitoring tools for lung conditions.

5

Shift our current research approach to develop earlier intervention.

6

Develop new treatments for lung conditions.

7

Accelerate inclusive recruitment to clinical trials.

8

Speed up the early adoption and roll-out of new diagnostic and intervention technologies.

9

Drive stronger collaboration across the sector.

10

Invest in the brightest minds.

You can be part of the change we need. Please get in touch to find out how to partner with us and deliver these priorities.

Priority 1

Promote the urgent need to progress respiratory research and innovation to transform health outcomes

There is undoubtedly an urgent need for greater respiratory research and innovation, but not the sense of urgency needed to drive it.

Every five minutes, someone dies from a lung condition in the UK[1]. Despite this, the culture of urgency that has driven advances in the care of conditions such as cancer and cardiovascular disease has not been seen for patients with lung conditions. While other medical conditions have seen significant progress in recent years, overall lung health has stood still.

Currently:

- More people are dying from a lung condition in the UK than anywhere else in Western Europe[4].
- Lung conditions cost the UK economy £188 billion a year, including nearly £10 billion directly on the NHS[5].
- Lung conditions have a stronger link with deprivation than any other disease. People with lung conditions who live in the most deprived areas are twice as likely to be admitted to hospital and die from a lung condition than those living in more affluent areas[6].

Negative or lacklustre attitudes towards lung health are partly driven by stigma, especially for conditions such as COPD which may be perceived as being self-inflicted[7]. However, there is growing evidence that a parent's history of smoking can increase the risk of their child developing a lung condition in adulthood, even if they stop smoking before their baby's conception.[8,9,10] Very early life events, such as being born prematurely[11] and having an early infection[12], have also been well evidenced as increasing the chance of lung problems later in life. To demonstrate the urgent need for investment in lung health research, we must use the findings from such studies to change the narrative that lung conditions are caused purely by behaviour as adults.

1.4 million
people in the UK have chronic obstructive pulmonary disease (COPD).

7.2 million
people in the UK have asthma.

212,000
people in the UK have bronchiectasis.

70,000
people in the UK live with pulmonary fibrosis.

11,000
people in the UK have cystic fibrosis.

9,000
people in the UK are estimated to live with primary ciliary dyskinesia (PCD).

4,500
cases of sarcoidosis are diagnosed in the UK each year.

1 in 13
preschool children in the UK will suffer from wheezing attacks.

What we are calling for:

Public funding into respiratory conditions to triple from £47 million to £141 million a year to bring the amount invested into respiratory research in line with the UK's health burden.

To achieve this, we need to find ways to convey the urgency and unmet need. The Lung Research and Innovation Group wants to work with partners, including charities and public health providers, to:

- raise public awareness of the personal and societal impacts of lung conditions, to reduce stigma and drive investment in respiratory research and innovation.
- encourage the nation to prioritise their lung health as much as heart or psychological health.

Priority 2

Identify and communicate top-level research goals for lung health

The major areas that respiratory researchers should address haven't yet been agreed and communicated.

While the **Life Sciences Vision** sets out the overarching ambitions of respiratory research and innovation, there needs to be clear, targeted respiratory goals for the research sector to rally around which are informed by those with lived experience. With so much unmet need and limited resource, prioritisation of goals is critical. We believe defining these research goals as 'grand challenges' will propel respiratory research forward, just as has been done for **cancer** and **mental health** research (other missions in the Life Sciences Vision).

The Lung Research and Innovation Group will develop 'grand challenges' for respiratory research and innovation, with input from people with lung conditions and researchers. These will be published in winter 2024.

What we are calling for:

- **All major research funding bodies to support the grand challenges created by the Lung Research and Innovation Group and help drive research activity in line with these shared priorities.**

> **"Lung conditions aren't glamorous, so they don't get the attention and funding they deserve. There is also the perception that some lung conditions are self-inflicted by smoking or working in dirty environments, which is often not the case. Not being able to catch your breath is really scary! You don't think about it really until you can't do it. We all have lungs and need our lungs to work to stay alive, so lung health and investment in research and innovation should be more of a priority."**
>
> Jenny, from Wimborne, living with asthma

Priority 3

Create a platform for lung health research

Progress in lung health research is hampered by a lack of good quality data and large patient cohorts.

Currently, datasets on lung health are poorly connected. We need to do more to improve the way data in different parts of our health service is used and shared, in particular sharing of data across primary, secondary and tertiary care. Better data sharing would help us understand the amount of people affected by diseases, determine when best to introduce tests and treatments so people can have better outcomes, and support clinical trials by providing a comparison for people receiving an intervention with people who have routine care (known as a control).

To understand who is at highest risk of developing lung conditions and how lung conditions develop over people's lives, we need to continue to invest in large research cohorts, such as **UKBiobank** and **Our Future Health**, and ensure that people who are living with lung conditions are included in these cohorts.

What we are calling for:

- **A continued commitment, with associated public or private funding, to collating respiratory data from primary, secondary and tertiary care to aid research by showing what happens to people with lung conditions over the course of their lives.**
- **The respiratory community to come together to secure a portion of the newly announced funding for artificial intelligence (AI) to drive progress in research and innovation. This could be used to identify drug targets or new therapeutics, and to make best use of CT scans in diagnosing not only lung cancer but other respiratory conditions.**
- **With the support of associated public or private funding, the development of new sub-groups (sub-cohorts) made up of patients with lung conditions in larger research cohorts, to help 'unpick' the causes of lung conditions.**

More people are dying from a lung condition in the UK than anywhere else in Western Europe.

Priority 4

Urgently develop better diagnostic and monitoring tools for lung conditions

A lack of diagnostic and monitoring tools is preventing timely diagnosis and effective management of lung conditions.

No one should be left struggling to breathe without a timely diagnosis or expert treatment. But for many people living with lung conditions, this is their reality.

1 in 4

people with COPD wait more than five years for a diagnosis. Around 1 in 12 wait more than a decade.

1 in 3

people with bronchiectasis wait more than five years for a diagnosis. 1 in 5 wait for more than a decade.

1 in 5

people with asthma wait more than five years for a diagnosis. 1 in 10 wait for more than a decade.

Patients with idiopathic pulmonary fibrosis may have symptoms for

5 Years

before a diagnosis is made.

Many patients are misdiagnosed because symptoms for different lung conditions often overlap, and effective diagnostic tools are lacking. In primary care settings in particular, a lack of skill in interpreting spirometry results (a test which measures how much air you can breathe out in one forced breath) and a lack of trained staff and equipment limits the universal usefulness of spirometry. This is a huge problem as it is the current gold standard for diagnosing asthma and COPD.

It is essential we develop faster and more accurate ways to diagnose infections such as those that affect people with cystic fibrosis, primary ciliary dyskinesia (PCD) and bronchiectasis. Swiftly treating infections with the appropriate medication is key to improve people's quality of life.

Measuring the progression of disease once diagnosed is hugely valuable to ensure that appropriate interventions and support are delivered at the correct time for people with lung conditions. For clinical trials, we need quicker-to-administer and reliable tests to show if new drugs for lung conditions are effective.

We also need to develop simple digital tools that can be used at home to assist with self-management. Development of remote monitoring tools can ensure more effective use of limited healthcare resources and offer people reassurance of oversight by a medical professional as they go about their daily activity. It is important that any new monitoring tools are easy to use and don't include lots of extra work or complex measurements to monitor a person's lung condition.

What we are calling for:

- **A multi-year investment to enable small- and medium-sized enterprises to develop and pilot alternative diagnostic and monitoring tools that are more accurate, lower in cost and easier to administer than those currently available.**
- **Longer-term investment in a centre for diagnosis for lung conditions. The centre could develop objective tests that can accurately differentiate between lung conditions. The centre should partner with existing initiatives such as the NIHR HealthTech Research Centres (HRCs), some of which are focused on diagnosis of respiratory conditions and infections.**

> **"I think more research into COPD (emphysema) is extremely important because today we don't understand the mechanism behind its development, so we don't really know how to stop, let alone reverse, the disease. As patients, we all live with an underlying permanent anxiety due to not knowing how our symptoms will progress – how fast and to what extent. Research is hope for the future."**
>
> Victor, from Stoke-on-Trent, living with COPD.

Priority 5

Shift our current research approach to develop earlier interventions

The current approach to interventions is too late for most lung conditions. Often they are detected late, once the damage to the lungs is already irreversible.

For many lung conditions, a person needs to show a limited lung capacity during a spirometry test to get a diagnosis. But at this point, the changes that have caused their lung capacity to become reduced are almost certainly permanent, making it extremely unlikely that the disease could be cured.

There needs to be a 'reframing' of lung conditions across the research and care system as something that can and should be detected early and appropriately treated and monitored. We need to research very early disease processes so that mechanisms can be understood, and targets identified for new treatments. Encouraging early detection can hopefully allow for intervention at a point where the beginnings of lung damage can be reversed.

Early life events such as prematurity and early lung infections as well as genetic factors can put children at higher risk of developing respiratory problems in the future. There is a window of opportunity for those experiencing poor lung health in early years, where we can help improve outcomes (as shown by studies where lung growth occurs spontaneously[13],[14] or potentially due to interventions such as exercise[15]), but more research is needed to determine what intervention to support improved lung function would look like. For those deemed at highest risk of developing lung problems, periodic lung function tests throughout their life would provide a more complete picture of lung function and more opportunities for intervention.

What we are calling for:

- **Dedicated funding to study early life influences (such as environment, early childhood infection, diet and prematurity) on the development of children's lungs. Based on this research, the development of targeted prevention/intervention strategies for those at highest risk of developing lung conditions later in life.**
- **Incidental findings from targeted lung health checks to be promptly followed up if they show conditions other than cancer. Participants should be given information about keeping their lungs healthy and directed to information about taking part in research.**
- **Lung fitness measurements to be included at baseline in large cohorts, ideally with follow-up measures at regular intervals, to help us understand risk factors for developing a lung condition and when to deliver intervention. This would also help us better understand the role of ageing in lung conditions.**

Priority 6

Develop new treatments for lung conditions

New treatments for lung conditions are urgently needed, which requires investment in research to repurpose existing treatments or develop new ones.

Biologics (specialist treatments that target specific cells in the body) have been a gamechanger for patients with severe asthma, highlighting the possibility of scientific breakthroughs for people with other lung conditions. But treatments for lung conditions remain far behind treatments for other diseases. We urgently need treatments that can stop or reverse disease progression, not just address the symptoms people have day-to-day.

- The therapeutic approach for COPD hasn't changed in more than 30 years[16].
- There are many people with asthma for whom there are no treatments that significantly modify the disease.
- There is no cure for idiopathic pulmonary fibrosis (IPF), which has a worse prognosis than some cancers, with an average survival of 3-5 years[17].
- There are currently no licenced treatments for bronchiectasis[18].
- Treatments for genetic diseases such as PCD, where there is damage to the structure of the cilia, are not yet developed.
- Because many people with lung conditions experience repeated infections, new antimicrobial treatments are needed desperately to combat antimicrobial resistance. This is one of the top global public health threats whereby misuse and overuse of antimicrobials means they are becoming less effective.

What we are calling for:

- **A multi-year investment to increase opportunities to revitalise experimental medicine research. This could include implementing new technologies, such as AI, to identify new drug targets and new drugs.**
- **A multi-year investment into environmental drivers of disease, such as air pollution and viruses, that would help researchers to understand the causes of exacerbation (when symptoms of a lung condition become particularly severe). This would allow researchers to develop tailored strategies to prevent exacerbation and better target the interventions used to reduce symptoms.**


Lung conditions have a stronger link with deprivation than any other disease.

Priority 7

Accelerate inclusive recruitment to clinical trials

To accelerate the development and approval of new treatments, respiratory clinical trials must recruit fully and be run efficiently.

For treatments to develop and be approved, we also need to see huge improvements in respiratory clinical trials, which are currently vastly underrecruited[19]. This risks pharmaceutical companies choosing to do trials outside of the UK. If trials are not conducted in the UK, people with lung conditions cannot benefit from new experimental therapies while they are being trialled. This also has a knock-on effect for the UK economy and job creation.

We need to work as a sector to encourage conversations about research with patients at diagnosis, so it becomes 'business as usual' and embedded within clinical care. Ideally, the Department of Health and Social Care and NHS Trusts would prioritise respiratory trials in hospitals and primary care and make research a central aspect of clinical care.

The Lung Research and Innovation Group (LRIG) can lead the way in working with stakeholders in industry to ensure that criteria to take part in trials are more inclusive. While we acknowledge the need for robust data so that drugs can be approved by regulators, we need criteria on who is included or excluded for trials to be broader to ensure recruitment targets can be met, for example including people with more than one health condition (who are often excluded from trials).

Technology to monitor remotely could revolutionise the way trials are delivered and reduce travel for trial participants. Trial design also needs to change to using a platform trial design. Platform trials are different in that they are open-ended, meaning new interventions can be added, assessed, and removed as time goes on, without having to specify what they might be at the start.

A model like the Cystic Fibrosis Clinical Trials Accelerator Platform (CTAP) could be adopted across the respiratory health sector. The platform works to:

- encourage centres delivering trials to collaborate
- increase capacity for studies through funded roles
- showcase the UK as a desirable country to run trials, through working with pharmaceutical companies.

What we are calling for:

- **The development of a respiratory specific clinical trial accelerator modelled on the CTAP, with the support of government and research funders, including charitable funders. Such a model is designed to transform the way clinical research in the UK is carried out, including providing access to additional staff resources and speeding up approvals processes.**
- **Creating more opportunities to identify and promote the chance to take part in research to people with lung conditions, such as through targeted lung health checks.**

Priority 8

Speed up the early adoption and roll-out of new diagnostic and intervention technologies

Respiratory has been left behind in terms of the adoption and roll out of new diagnostic and self-management tools compared with other diseases.

Self-management technologies and remote monitoring platforms have an important role to play in improving outcomes for people with lung conditions. We know regular supported self-management reduces the use of healthcare resources and improves quality of life across all levels of asthma severity[20] and has the potential to do the same for other respiratory conditions such as cystic fibrosis and bronchiectasis.

Generating evidence to achieve adoption is prohibitively expensive, and existing pathways to adoption are built around high-risk interventions like new drugs and not low-risk interventions like apps. Researchers running even small studies are required to apply for regulatory status and establish early diagnostic accuracy before they can carry out clinical research with new devices. Thresholds of evidence for regulation (required by the MHRA), recommendation (required by NICE) and adoption (required by the NHS) need further refinement to accommodate rapid innovation and new technologies.

New technologies are not being adopted by NHS providers, despite the efforts of NHS England, the Accelerated Access Collaborative (AAC) and the Health Innovation Network (previously the AHSN Network). We need to identify ways to speed up the early adoption and roll-out of new technologies that meet unmet needs for both patients and the health service, particularly low-risk, high-impact innovations.

What we are calling for:

- **That authorities who have a role in approving and recommending new devices and technologies, such as the MHRA and NICE, review their evidence thresholds. The amount of evidence required needs to fairly mitigate risk while not being prohibitively excessive.**
- **A rebalance of the funding available for early-stage research towards the development and adoption of new tools through mechanisms such as the Health Innovation Networks and the NHS AI Lab.**
- **To facilitate the accelerated uptake of innovation and deliver best value for the NHS, accelerating existing initiatives such as Health Tech Value Based Procurement and the Early Value Assessment. These processes seek to help the NHS assess health products and technologies faster so that patients can benefit from them sooner.**

Lung conditions cost the UK economy £188 billion a year.

Priority 9

Drive stronger collaboration across the sector

Historically, respiratory researchers have often worked in disease silos, which limits progress. Instead, focusing on the cross-cutting themes of lung conditions could have a larger impact.

We need to engage with researchers across a much wider range of disciplines than those traditionally engaged with through respiratory research to address complex health challenges which also have behavioural, societal, economic and environmental influences (for example, by working with researchers in mental health, ageing and environmental science). It is also important to consider people living with other multiple long-term conditions in addition to lung conditions, which is only going to become more relevant with our growing ageing population.

We need better collaboration across primary, secondary and tertiary care to deliver research. Primary care and allied health professionals should be encouraged to be leads or co-leads of research programmes rather than just delivering them.

What we are calling for:

- **Research funders to support a 'Healthy Lungs Centre of Excellence'. Institutes in the Centre would work on a common research programme focusing on cross-cutting issues that affect lung health, such as a better understanding of the causes of breathlessness and developing treatments for breathlessness, or the role of viruses in exacerbation of lung conditions. This would encourage researchers from different institutions, sectors (including primary and specialist settings) and research stages (basic, translational and clinical research) to work together to solve problems.**

Priority 10

Invest in the brightest minds

Training and career development issues within respiratory research and innovation are stalling the talent pipeline.

The research and innovation workforce struggles to retain researchers based in non-clinical settings due to a lack of continuity in funding. Additionally, staff with medical training (such as doctors or nurses) who want to pursue research training alongside performing clinical work lack options and funding to train and find it hard to take time out of clinical work.

We need to support the recruitment of outstanding world-class respiratory leaders, both basic science and clinical academics, and attract new talent into a career focused on respiratory research. Without the next generation of research leaders, there will be nobody to conduct the cutting-edge studies required to drive forward improvements in clinical care, which includes running clinical trials.

What we are calling for:

- **An increased investment into government-funded career development awards, increasing the numbers and types of clinical development awards for respiratory medics, nurses and allied health professionals to develop their research skills. Industry could support research stipends to be distributed through charitable funders in an impartial way.**
- **A recognition of the value of allocating time in clinical careers to develop research skills by building in protected research time in respiratory medic, nursing and allied health professional roles. This should include time to evaluate new innovations and enable joint posts to allow NHS clinicians to work in industry.**
- **Increased investment in career development pathways for basic and translational scientists working in not-for-profit settings.**

Our urgent message

Despite the fact that **1 in 5** of us will have a lung condition in our lifetime, lung health in the UK isn't being taken seriously. With the support of charities, government, people with lung conditions and the public, **we can improve the outlook for those living with a lung condition.**

If the government and other key stakeholders **invest in the 10 respiratory research priorities** outlined in this report, we will improve lives, make huge savings for the healthcare system and serve the needs of the 12 million people in the UK who will develop a lung condition in their lifetime.

Our goal is to reduce the number of people who face the horrifying situation of not being able to breathe. Get in touch to find out more about how you can work with us to deliver these priorities.

Investment in our 10 priorities will save lives.

About this report

This publication is authored and supported by:

LRIG research advisers

Professor Eric Alton, Imperial College London

Dr Lisa Brighton, King's College London

Dr Hannah Durrington, University of Manchester

Professor Ian Hall, University of Nottingham and co-Chair of LRIG

Professor Clare Lloyd, Imperial College London

Professor Jenni Quint, Imperial College London

Professor Cliff Taggart, Queen's University Belfast

LRIG organisation members

Action for Pulmonary Fibrosis

Association of British Healthtech Industries

Asthma + Lung UK

British Association for Lung Research

British Thoracic Society

Cystic Fibrosis Trust

LifeArc

NIHR Respiratory Translational Research Collaborative

Primary Care Respiratory Society

Pulmonary Fibrosis Trust

Sarcoidosis UK

For more information about this report contact:

Dr Samantha Walker
swalker@asthmaandlung.org.uk

Cheryl Routley
croutley@asthmaandlung.org.uk

References

1. British Lung Foundation. 2016. *The battle for breath: the impact of lung disease in the UK*. Accessed March 2023; accessed **here**.
2. Office National Statistics. 2022. *Death registration summary statistics, England and Wales: 2022*. Accessed March 2024; accessed **here**.
3. UK Clinical Research Collaboration. 2023. *UK Health Research Analysis 2022*. Accessed February 2024; accessed **here**.
4. Asthma + Lung UK. 28th February 2022. *Lung conditions kill more people in the UK than anywhere in Western Europe.* Accessed February 2024; accessed **here**.
5. Asthma + Lung UK. 2023. *Investing in breath: reducing the economic cost of lung conditions through increased research and innovation.* Accessed March 2024; accessed **here**.
6. Asthma + Lung UK. 2023. *Breathing Unequal: Examining health inequalities and lung conditions.* Accessed March 2023; accessed **here**.
7. Mathioudakis AG, et al. Stigma: an unmet public health priority in COPD. *Lancet Respir Med*. 2021 Sep;9(9):955-956.
8. Guerra S, et al. Combined effects of parental and active smoking on early lung function deficits: a prospective study from birth to age 26 years. *Thorax*. 2013 Nov;68(11):1021-1028.
9. Svanes C, et al. Father's environment before conception and asthma risk in his children: a multi-generation analysis of the Respiratory Health in Northern Europe study. *Int J Epidemiol*. 2017 1;46(1):235-245.
10. Li YF, et al. Maternal and grandmaternal smoking patterns are associated with early childhood asthma. *Chest*. 2005 Apr;127(4):1232-1241.
11. Bui DS, et al. 2022 Association between very to moderate preterm births, lung function deficits, and COPD at age 53 years: analysis of a prospective cohort study. *Lancet Resp. Med.* 2022 May;10(5):478-484.
12. Collaro AJ, et al. The effect of early childhood respiratory infections and pneumonia on lifelong lung function: a systematic review. *Lancet Child Adolesc Health.* 2023 Jun;7(6):429-440.
13. Bui DS, et al. Childhood predictors of lung function trajectories and future COPD risk: a prospective cohort study from the first to the sixth decade of life. *Lancet Respir Med*. 2018 Jul;6(7):535-544.
14. Belgrave DCM, et al. Lung function trajectories from pre-school age to adulthood and their associations with early life factors: a retrospective analysis of three population-based birth cohort studies. *Lancet Respir Med.* 2018 Jul;6(7):526-534.
15. Koch S, et al. Physical activity and body mass related to catch-up lung function growth in childhood: a population-based accelerated cohort study. *Thorax*. 2024 Mar 6: thorax-2022-219666. doi: 10.1136/thorax-2022-219666. Epub ahead of print. PMID: 38448222.
16. Stolz D, et al. Towards the elimination of chronic obstructive pulmonary disease: a Lancet Commission. *Lancet. 2022* Sep 17;400(10356):921-972.
17. Spencer LG, et al. Idiopathic pulmonary fibrosis in the UK: analysis of the British Thoracic Society electronic registry between 2013 and 2019. *ERJ Open Res.* 2021 Jan 25;7(1):00187-2020.
18. The Lancet Respiratory Medicine. New developments in bronchiectasis. *Lancet Respir Med*. 2023 Sep;11(9):755.
19. Association of British Pharmaceutical Industries. 2022. *Rescuing patient access to industry clinical trials in the UK*. Accessed December 2023; accessed **here**.
20. Hodkinson A, et al. Self-management interventions to reduce healthcare use and improve quality of life among patients with asthma: systematic review and network meta-analysis. *BMJ*. 2020 Aug 18;370:m2521. Erratum in: *BMJ.* 2023 Jul 27;382:p1743.

Asthma + Lung UK
The White Chapel Building
10 Whitechapel High Street
London SE1 8QS

0300 222 5800
info@asthmaandlung.org.uk
AsthmaAndLung.org.uk