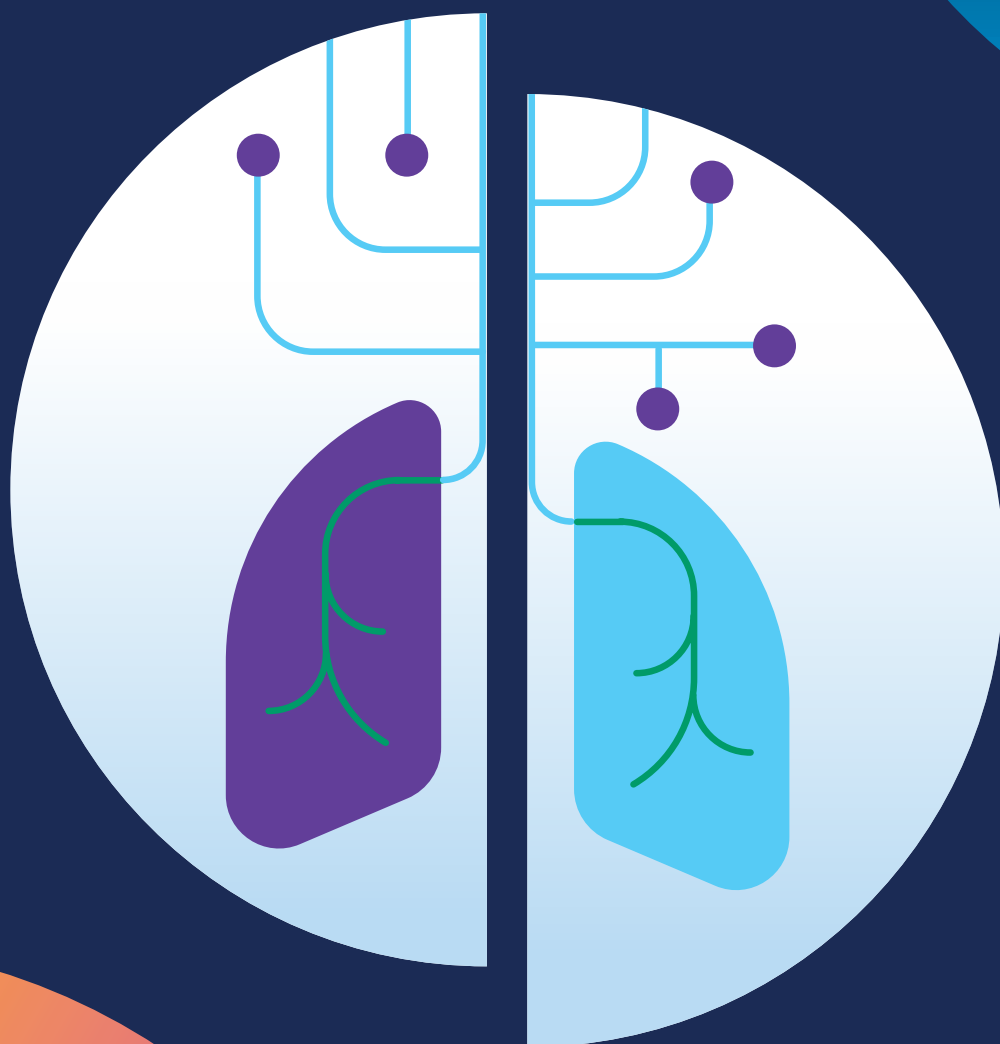


Transforming Respiratory Diagnostics: The way forward



Joint report prepared by





Contents

Executive Summary	2
Foreword	4
Respiratory Disease: the scale of the challenge	6
Patient Perspectives	8
What are the challenges faced by people with respiratory disease?	10
How can respiratory diagnostics help to address these challenges?	14
Next Steps	16

Executive summary



Around 12 million people, one in five of the UK population, will develop a lung condition during their lifetime. It is one of the three biggest killers claiming the lives of 115,000 people each year, the equivalent of one every five minutes.

Despite their prevalence and impact on people's lives, respiratory diseases receive disproportionately low research funding and public attention compared to other common illnesses. Furthermore, stark disparities persist in lung health outcomes, rooted in socio-economic and environmental factors, exacerbating inequalities among vulnerable populations.

Diagnosing respiratory illnesses and identifying when there's something wrong with the lungs is a particular challenge. People can wait many months and sometimes years to get diagnosed despite the fact that diagnosing respiratory illnesses is essential for providing appropriate treatment, preventing the spread of disease, avoiding complications, optimising public health responses, identifying underlying conditions, and improving quality of life for affected individuals.

In November 2023, LifeArc and Asthma+Lung UK held a workshop on 'Transforming Respiratory Diagnostics' at the Royal Society in London. It brought together a diversely skilled group of 100 people – including clinicians, academics, innovators and people living with respiratory disease. The perspectives and proposals from this event highlight emerging ideas set to influence future strategies in the development and integration of diagnostic and screening tools for respiratory conditions. This report explores the pressing challenges and opportunities surrounding respiratory diagnostics,

Every
5 minutes
someone will die due
to a lung condition

aiming to catalyse transformative advancements in lung health care. It highlights the key challenges faced by individuals with respiratory diseases, including delays in diagnosis, inadequate access to care, and the unpredictability of exacerbations. It outlines the critical role of improved respiratory diagnostics in addressing these challenges, offering opportunities for precise disease detection, personalised treatment, and patient empowerment. Collaboration among stakeholders, including researchers, healthcare providers, patients, and funders, is essential for driving progress in this area.

Key priority areas where improved respiratory diagnostics could offer the potential to radically improve people's lives include:

- the development of a lung health indicator for early risk prevention
- accessible diagnostic tools for primary care environments
- stratification tools to guide informed treatment decisions
- disease monitoring tools for early intervention and prevention of exacerbation

Foreword

Lung conditions
cost the NHS

£10 billion

every year

Costs the UK

£188

billion a year



We can often take breathing for granted. But imagine a reality where every breath is a struggle. Imagine your symptoms are gradually worsening, yet no one can pinpoint what's wrong. Imagine not knowing when you may experience a sudden and severe attack that lands you in a hospital emergency ward. Imagine the heartbreak of losing a loved one to a respiratory disease – and knowing their death could have been prevented.

Lung conditions
are the

3rd

biggest killer in
the UK

Lung conditions are the third biggest killer in the UK. As well as the huge impact they have on people's lives, there is also a staggering economic toll. They cost the UK £188 billion a year, including nearly £10 billion in direct costs for the NHS. Yet, despite claiming a life every five minutes, respiratory diseases lack the attention afforded to other common illnesses like cancer or cardiovascular disease. Only 1.8% of government and charity research funding is allocated to lung conditions, which is disproportionately lower than their overall burden suggests.

Furthermore, stark disparities persist in lung health, which are largely rooted in socioeconomic and environmental factors and disproportionately affecting the most vulnerable in society. For a person in the UK living with a lung condition such as asthma, bronchiectasis or chronic obstructive pulmonary disease (COPD), where they live and how wealthy they are will significantly impact their ability to manage their lung condition effectively, how often they go to hospital, and their chances of living a long life.

This is not fair and it needs to change. It's time to raise awareness of the devastating impact of respiratory diseases on people's lives, generate a sense of urgency, and change attitudes toward lung health to address these pressing challenges.

Now envision a world where easily accessible and precise diagnostic tests are available for respiratory diseases. Advanced screening tools can identify potential issues even before symptoms occur, empowering individuals to take proactive steps to prevent them from developing a lung condition. People with breathing difficulties can quickly get a diagnosis, enabling prompt access to tailored treatments. Additionally, state-of-the-art monitoring tools can continually keep track of their disease, allowing for adaptive and timely adjustments to their treatment plan.

Thanks to rapid advances in technology, we have a unique opportunity to catalyse this transformative shift. However, this will require people who are all determined to drive progress in lung disease to come together and make it happen.

Together, we can bring in a future where breathing is no longer a struggle but a right enjoyed by all.



Respiratory disease: the scale of the challenge

Around 12 million people, one in five of the UK population, will develop a lung condition during their lifetime.

Lung diseases affect the respiratory system and prevent someone from breathing properly. They include a wide range of conditions, from asthma and COPD, bronchiectasis, infections such as pneumonia and flu, and less common diseases such as interstitial lung disease.

1 in 5 people in the UK will develop a respiratory disease in their lifetime.¹

1.4 million people in the UK have COPD –

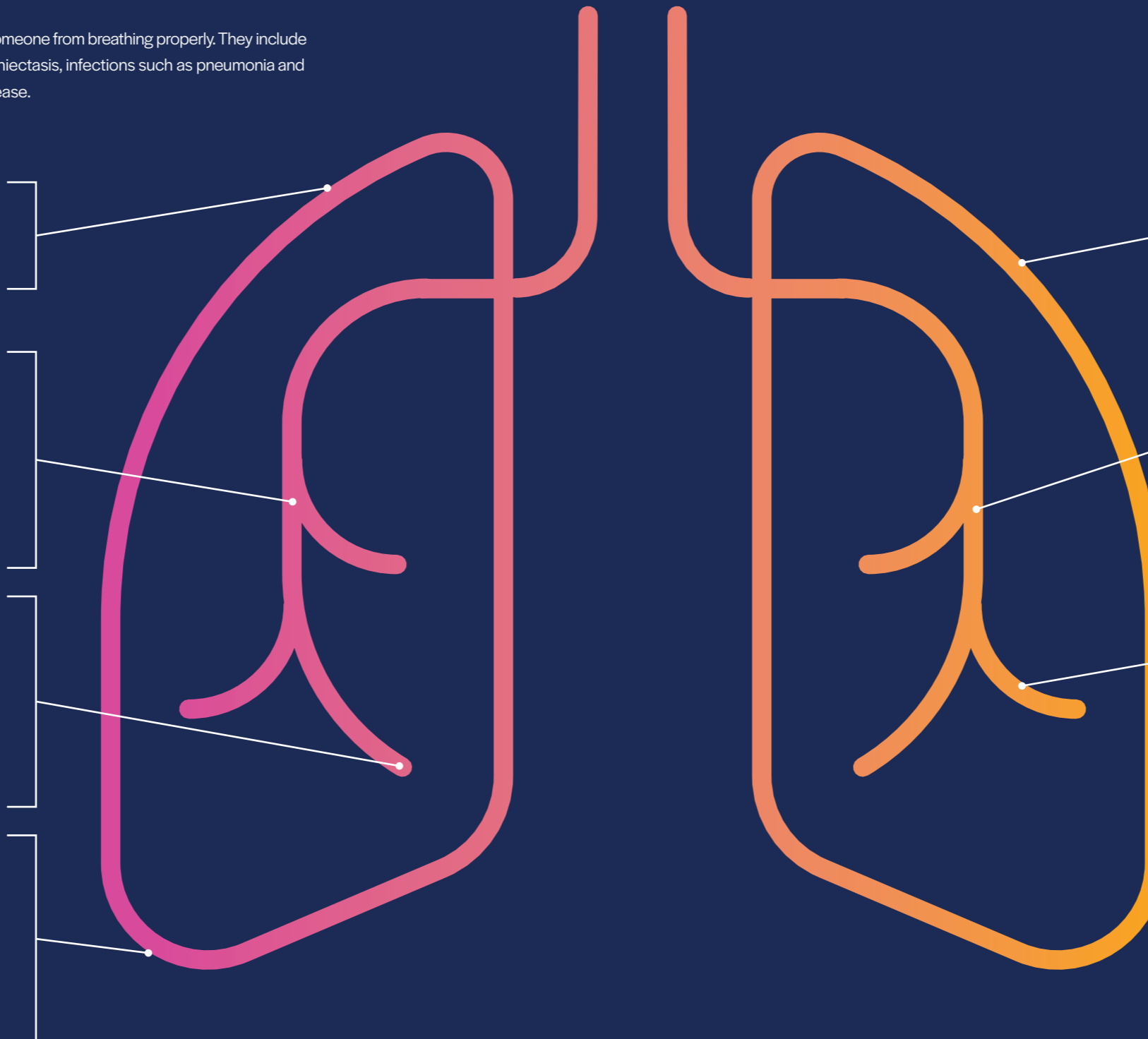
a lung disease causing restricted airflow and breathing difficulties. It includes emphysema (damage to the air sacs in the lungs) and chronic bronchitis (long-term inflammation of the airways).²

7.2 million people in the UK have asthma –

a long-term condition where the airways can become narrowed and inflamed at times, making it harder to breathe and causing potentially fatal asthma attacks.³

212,000 people in the UK are living with bronchiectasis –

a long-term condition where the airways of the lungs become widened, leading to a build-up of mucus that can make the lungs more vulnerable to infection.⁴



Disparities in lung health

In England, it's a tragedy that people living in the poorest areas will die many years earlier than those in the richest areas, reflecting health inequalities – preventable differences in health outcomes across different population groups within society.

We have known for a long time about the close relationship between lung conditions and health disparities.

These illnesses are caused and/or triggered by exposure to things that are often related to socioeconomic status, including air pollution, poor housing, smoking, occupational hazards and access to healthcare services. All these factors are drivers of unacceptable health disparities in lung health – and there is an urgent need to address this burning injustice.

220,000 people are diagnosed with pneumonia each year in the UK.⁵

102,500 people in the UK are living with interstitial lung disease – a group of diseases including pulmonary fibrosis and sarcoidosis that cause scarring (fibrosis) of the lungs.⁶

1 in 13 preschool children in the UK will suffer from wheezing attacks – and around 1 in 3 of these young children will go on to develop asthma by school age.⁷

57% of all antibiotics prescribed in Europe are for upper respiratory tract infections, with a further 30% for lower respiratory tract infections.⁸

*For references, please see back page.

Patient perspectives

“ I feel like there’s an elephant on my chest, and it won’t get off.”

Bryony was diagnosed with brittle asthma at the age of six. Her condition can cause sudden serious attacks that can be life-threatening.



“ It’s a disease that also affects younger people who have their whole lives ahead of them.”

“Felix took ill in November 2017. He was up all night feeling ill. We took him to the hospital the next day. They realised he had pneumonia and pretty quickly he went into intensive care. He then just went downhill over three or four days.

He was put on life support, which they thought he’d be on for about five days, and it ended up being 37 days. As a result of that, he had to have lots of rehab. It was there when he had scans that showed that he had bronchiectasis.

“They said we’d need to do airway clearance with him every day, but we didn’t know that would be an ongoing thing. We’re six years later now and he’s still doing it. We go to check up every six months and they look at his lung function and he takes the antibiotics every other day.

“Felix is now 14 years old. He’s a very outgoing gregarious boy. He likes cycling and gaming. He’s currently obsessed with fishing. I feel really sorry that he has to deal with it, I think it’s not fair. I also feel really proud of him, that he deals with it so well. He just gets on with stuff and doesn’t let it stop him do things.”

“When people think about bronchiectasis, or any long-term chronic lung condition, people tend to think of older people – and rightly or wrongly, they may think it was their fault.

But bronchiectasis can also occur in younger people, it can occur from birth, it can suddenly hit an otherwise healthy individual if they go through an illness. It’s a disease that also affects younger people who have their whole lives ahead of them. I feel that research must look at helping people have a long life and cope with the condition.”

Charlotte Wright

Charlotte’s son, Felix, was diagnosed with bronchiectasis at the age of six. He needs to undergo daily airway clearance to remove the mucus that builds up in his lungs.



“ I’m known as a silent wheezer so there’s no air getting down to my lungs. I just feel like there’s an elephant on my chest, and it won’t get off.”

“I didn’t want the medical attention, I needed it. There will be a point where I just crash. Resus is traumatic because you can hear everything that’s going on. And then obviously you start to see – and there all these people sticking needles into you, but you can’t communicate. And when you come around, they just leave.

“At 20 years old, I was on a mobility scooter at home. I had no life. My partner was my carer. You’re just focusing on your health. It’s had a great impact on my mental health.

“I’m now 25 years old and I’ve been well for three years.

It’s taken three different biologics to get me where I am now. I’m on dupilumab. I’d say it’s a miracle. Two and a half years ago I got a job at the hospital, and I now work in the paediatric ward where I was frequently a patient for 18 years. It’s a bit surreal.

“Unfortunately, my body does get used to medications and that’s what I dread for the future. Therefore, the research needs to continue, and other biologics do need to be created. But for now, I’ll just hold onto that hope and live the life that I’ve got at the moment.”

Bryony Saint

“ The whole thing of diagnosis was awful – because you’re so ill and you just couldn’t get help.”

“I got a really bad lung infection when I was about 59. It wasn’t just one lung infection – I had another two within that year. So I went to see my GP and she asked me if I smoked, and I said no I don’t. And she listened to my chest, and she said there’s no crackle, you’re fine – everybody’s got a cough you’ll get better in summer, which I didn’t think was very helpful.

“When I got the next infection, I was sent to the local hospital – and they ruled out cancer straight away. But it took another nine months before I got a diagnosis with COPD.

“The whole thing of diagnosis was awful – because you’re so ill and you just couldn’t get help. It was not a great time. In the future, I’d really like to see early diagnosis for people. At the moment, a lot of people are waiting for a diagnosis. The longer you leave it, the more likely you are to get your lungs more and more damaged.

“My advice to other people who have been newly diagnosed with a lung condition like mine is to make sure you’re doing everything you can to stay fit and well. Things like swimming, walking, and even going upstairs are really important.

“I’m short of breath most of the time but actually I can ignore it. I can swim for a mile. I’ve got a flute, I’ve got a bicycle. I am refusing to accept that you need to change your lifestyle. My mum was only diagnosed when she was 87 and she lived to 94, and I’m planning to do much the same!”

Felicity Payne



Felicity is 67 years old and lives in Eastbourne. She struggled to get a diagnosis of the cause of her breathing difficulties.

What are the challenges faced by people with respiratory diseases?

One in five people who experience frightening symptoms like breathlessness, wheezing and coughing delay seeking help. Even then, they face delays to diagnosis, complex tests, and poor access to the care they need.

1. Lack of opportunities to prevent disease

Currently, the focus is on identifying and treating respiratory conditions rather than maintaining lung health. Changing this paradigm will require a shift toward proactive approaches, supported by long-term population studies and effective preventative interventions targeting high-risk groups.



2. Delays in receiving a timely diagnosis

“Current diagnostics is like ringing the fire alarm after the house has burnt down.”

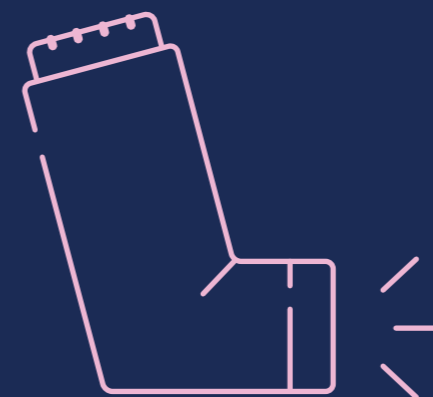
Delays in diagnosis are pervasive, with significant proportions of patients enduring prolonged waits, reflecting systemic deficiencies in diagnostics and care pathways.

The process of getting a respiratory diagnosis is complex, often inaccurate and requires specialist centres and equipment. Delays can be introduced at many different points in this multi-stage process:



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

Around one in three people with bronchiectasis wait more than five years for a diagnosis. One in five wait for more than a decade.



Around one in five people with asthma wait more than five years for a diagnosis. One in ten wait for more than a decade.

• **Before seeing the GP**

Early symptoms, such as a cough, shortness of breath, or fatigue, can be non-specific and overlap with symptoms of other health issues. Respiratory conditions typically have a chronic and progressive nature, with symptoms developing slowly over time, apart from asthma which often fluctuates in severity from day to day and month to month over many years. People may initially attribute their symptoms to other factors, such as aging or a common cold, and delay seeking medical attention.

• **At the GP**

Access to timely and accurate diagnostic tools remains limited, exacerbating delays and hindering effective treatment strategies.

GPs lack the necessary tools to enable them to decide whether there is something seriously wrong with a patient's lungs that requires further investigation. As a result, they may initially advise the patient to come back if their symptoms don't improve – and/or prescribe inappropriate treatments, such as antibiotics, which are unlikely to work.

• **At secondary care**

Respiratory symptoms can be caused by various conditions, each requiring a distinct approach to diagnosis. A specialist may need to consider multiple potential diagnoses and rule them out one by one, which can lengthen the time it takes to confirm a diagnosis with a specific condition.

As part of this process, the patient may need to undergo several tests or procedures, such as scans, lung function tests, and sometimes invasive procedures like bronchoscopy or lung biopsies. Waiting for appointments and test results can cause further delays, especially if additional tests are required based on the initial findings.

Spirometry is a common lung function test that can provide information of the volume and speed of airflow during breathing. It requires the patient to breathe into a tube to see how much air they can breathe out in one forced breath and how quickly they can blow it out. While it can demonstrate issues with airflow, the technique has several limitations as a diagnostic tool including it:

- requires access to a spirometry device – and the appropriate level of expertise to interpret the results.
- is effort dependent and many patients with respiratory conditions find it difficult to perform.
- isn't suitable for everyone – including people with heart problems or children under five years of age.
- can often give highly variable results, particularly if the patient isn't experienced at the technique.
- does not determine the cause of airflow limitation.

3. Delays in getting the right treatment

“The greatest unmet need is time to diagnosis. There are several opportunities to improve this: phenotyping at diagnosis rather than trial by therapy.”

There is an increasing recognition of the diversity within specific respiratory conditions, leading to the concept of 'endotypes' – or groups of patients whose disease is caused by a common biological mechanism. The ability to distinguish disease endotypes holds the promise of stratifying patients, enabling a more targeted and personalised approach to respiratory care. However, there is currently a lack of biomarkers or diagnostic tools to stratify patients into disease endotypes. Currently, doctors will use a 'test and learn' approach – cycling through various treatments sequentially until the most effective one is identified. This process can introduce unnecessary delays and potentially further lung damage.

4. Living with the unpredictability of exacerbations

Exacerbations – acute episodes or flare-ups of symptoms – are a common feature of many respiratory conditions and can significantly impact a person's health and quality of life. If not promptly and effectively managed, these episodes can be life-threatening. Frequent hospitalisations can disrupt daily life, cause emotional stress, and impact a person's ability to work or engage in social activities. Exacerbations cause damage to the lungs and repeated episodes contribute to a progressive decline in lung function over time.

Recognising symptoms early and intervening promptly during exacerbations are crucial to mitigate their impact and improve long-term outcomes for patients. However, traditional monitoring tools lack the sensitivity required to detect subtle changes preceding exacerbations and intervene promptly.

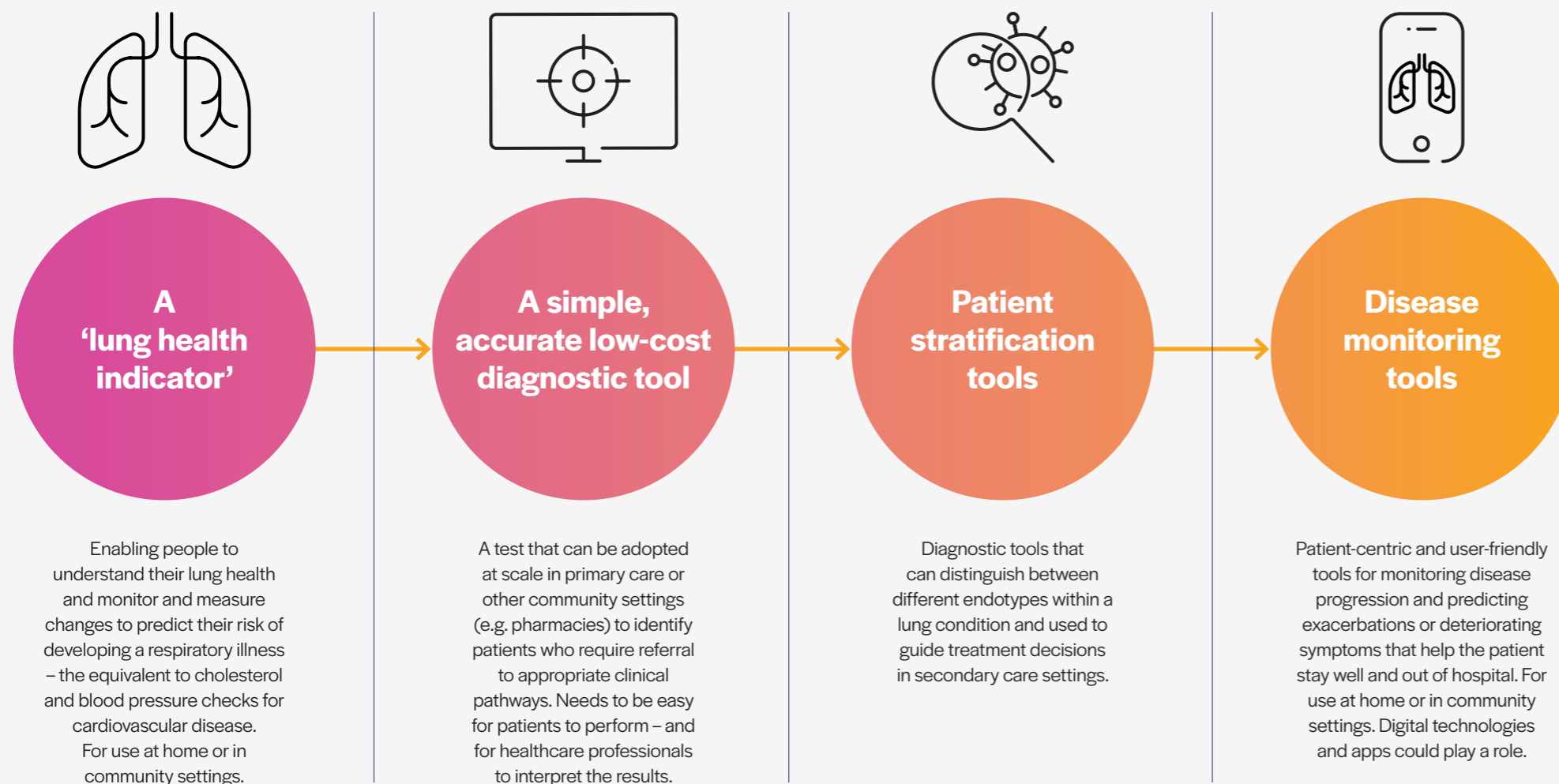
An ideal disease monitoring tool would:

- use validated biomarkers to measure and understand what's 'normal' for each patient – and spot any changes promptly that may require intervention.
- measure and collect changes over time – ideally, through passive monitoring that doesn't require data input and can be built into everyday technologies like mobile phones.
- provide clinicians with additional information beyond pathogen testing that can help them decide how and when to adapt treatment.



How can respiratory diagnostics help to address these challenges?

Improved respiratory diagnostics offer opportunities for precise and timely detection of lung conditions, facilitating personalised care approaches and empowering patients to actively manage their health.



Key benefits

- Disease prevention**
 Monitoring and measuring changes in lung health could help identify people at increased risk of respiratory conditions who may benefit from targeted interventions to prevent or delay the onset of disease. Improving awareness through better monitoring could also lead to overall improvements in lung health among the general population.
- Early intervention and treatment**
 Saving and improving people's lives starts with a timely and accurate diagnosis. Early diagnosis and prompt treatment could help to slow down disease progression.
- Better disease monitoring**
 Chronic respiratory diseases are dynamic, with symptoms and lung function changing over time. Advanced diagnostics that allow for continuous monitoring of disease progression could enable doctors to adjust treatment plans based on the evolving needs of the patient and alert patients to the need to take action to stabilise symptoms or seek medical help.
- Preventing exacerbations**
 Better diagnostics could help identify individuals at risk of exacerbations, allowing doctors to implement preventive measures and prompt interventions to avoid acute worsening of symptoms.
- Personalised treatment**
 Advanced diagnostics could enable doctors to tailor treatment plans based on the specific characteristics of the disease in each patient, leading to more effective and targeted interventions.
- Empowering patients**
 A better knowledge about their lung health will allow individuals to actively participate in their healthcare decisions, adhere to treatment plans, and make lifestyle changes that can positively impact their respiratory health.
- Facilitating research and drug development**
 The lack of diagnostic or screening tools for respiratory conditions is a huge barrier to progress in research and innovation. Accurate diagnostics contribute to a better understanding of the underlying mechanisms of respiratory diseases, which is crucial for the development of new and more effective treatments. Better biomarkers and tests are also required to stratify patients for testing treatments in the right populations in clinical trials – for example, those with early-stage disease.
- Reduced healthcare costs**
 Chronic respiratory diseases often lead to repeated hospitalisations and emergency care, contributing to high healthcare costs. Improved diagnostics can facilitate the development of more cost-effective and efficient care pathways, reducing the economic burden on healthcare systems.

Next steps

This report highlights the urgent need for a step-change in how lung diseases are detected, treated and managed. Achieving this transformational shift will only happen through collaboration.



LifeArc and Asthma + Lung UK are exploring the key themes and priorities for focus and investment identified during the discussions at the workshop. We will work in partnership with other organisations to develop and launch initiatives aimed at revolutionising respiratory diagnostics.

This report highlights key priority areas where improved respiratory diagnostics offer the potential to radically improve people's lives. These include the development of a 'lung health indicator' for early risk prediction, accessible diagnostic tools for primary care settings, stratification tools to guide treatment decisions, and disease monitoring tools for early intervention and exacerbation prevention. These innovations promise to transform respiratory care, promoting disease prevention, early intervention, personalised treatment, and patient empowerment while reducing healthcare costs and fostering research and drug development.

As a first step, we will pinpoint areas where we believe our collective efforts will yield tangible results for patients. We will work together to develop target product profiles to guide the development of appropriate tools and tests. We will also need to build pipelines, foster networks and creating an innovative environment that will accelerate the development and delivery of innovative diagnostic tools.

As our plans evolve, we will engage with other stakeholders with relevant insights and expertise who can help us build on the themes we've identified so far. These include researchers, diagnostic companies, funders and people living with lung disease. Our goal is to enable people with lung conditions to live longer with an improved quality of life by transforming respiratory diagnostics.

Together, we can make this happen.
Join us in making this vision a reality.

If you would like to contribute your ideas, please contact us we would love to hear from you.



Dr Samantha Walker
Director of Research & Innovation

Asthma + Lung UK
swalker@asthmaandlung.org.uk



Dr Catherine Kettleborough
Head of Chronic Respiratory
Infection Translational Challenge

LifeArc
Catherine.Kettleborough@lifearc.org



LifeArc

Lynton House,
7-12 Tavistock Square,
London WC1H 9LT
lifearc.org

Asthma + Lung UK

The White Chapel Building,
10 Whitechapel High St,
London E1 8QS
asthmaandlung.org.uk



References:

1. The International Respiratory Coalition's data portal <https://international-respiratory-coalition.org/countries/uk/>
2. Stone et al <https://pubmed.ncbi.nlm.nih.gov/37497381/>
3. Health Survey for England[i]; Health Survey Northern Ireland[ii], The Scottish Health Survey[iiii], Welsh Health Survey[iv]
 1. <https://digital.nhs.uk/data-and-information/publications/statistical/health-survey-for-england/2018>
 2. <https://www.nisra.gov.uk/statistics/find-your-survey/health-survey-northern-ireland#toc-5>
 3. <https://www.gov.scot/publications/scottish-health-survey-2022-volume-1-main-report/>
 4. <https://www.gov.wales/welsh-health-survey>
4. Snell et al [https://www.resmedjournal.com/article/S0954-6111\(19\)30299-9/fulltext](https://www.resmedjournal.com/article/S0954-6111(19)30299-9/fulltext)
5. <https://www.asthmaandlung.org.uk/battle-breath-report>
6. The International Respiratory Coalition's data portal <https://international-respiratory-coalition.org/countries/uk/>
7. Bloom et al: <https://pubmed.ncbi.nlm.nih.gov/33453287/>
8. Llor & Bjerrum <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4232501/>