

Bronchiectasis in the UK

A hidden burden
that demands
better care

Policy brief

July 2026

Initiated and funded by Insméd
Job Bag No: NP-BE Med-UK-00027
Date of preparation: July 2026



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Funding disclaimer

Bronchiectasis Policy Network UK is a multi-stakeholder alliance, initiated and funded by Insmed Ltd. Secretariat is provided by The Health Policy Partnership, an independent health research and policy consultancy. The activities and outputs of the network are guided by members. Most members are remunerated for their time, except Alex Fynney (on behalf of Asthma + Lung UK) who provided their time on a voluntary basis. All outputs from this group are above brand, non-promotional, evidence based and shaped by the network members, who hold editorial control. Insmed Ltd have reviewed the content for factual accuracy and compliance with pharmaceutical companies regulations.

ABOUT THIS REPORT

This policy brief has been developed to shine a light on the underrecognised and overlooked impact of bronchiectasis in the UK and provide recommendations for change. It is based on desk research and interviews with healthcare professionals and patient advocacy experts from across the UK. The development of the policy brief was guided by Bronchiectasis Policy Network UK – a multidisciplinary group of stakeholders who are working together to champion improved bronchiectasis care and elevate the prioritisation of this condition among system leaders.

This evidence-based policy brief was initiated and funded by Insmmed Ltd. Analysis and drafting were led by Aislinn Santoni and Jody Tate, and the text was edited by Mo Forman and Kasia Trojanowska of The Health Policy Partnership. Draft outputs were shared with expert contributors for their feedback and final approval.

This policy brief has been endorsed by:



Scottish Thoracic
SOCIETY

ACKNOWLEDGEMENTS

We are grateful to the members of Bronchiectasis Policy Network UK, who helped to shape and guide this policy brief:

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- Dr Jamie Duckers, Bronchiectasis Service Lead; Cardiff and Vale University Health Board and Health Care Research Wales Respiratory Lead; Trustee of Asthma + Lung UK
- Prof. Tom Fardon, Consultant Physician in Respiratory and General Internal Medicine, NHS Tayside
- Alex Fynney, Policy Officer, Asthma + Lung UK
- Dr Kevin Gruffydd-Jones, General Practitioner, Box, Wiltshire
- Dr Martin Kelly, Respiratory Consultant, Altnagelvin Hospital, Derry, Northern Ireland
- Dr Fiona Mosgrove, General Practitioner with a Special Interest (GPWSI) Respiratory Medicine, NHS Grampian
- Prof. Jennifer Quint, Professor of Respiratory Epidemiology, School of Public Health, Imperial College London

- Prof. Alan Timothy, patient expert
- Naomi Watt, Respiratory Nurse Specialist; Healthcare Professional Engagement Manager, Asthma + Lung UK
- Prof. Tom Wilkinson, Professor of Respiratory Medicine, University of Southampton

We would also like to thank the following experts, who contributed their insights:

- Anna Alderslade, Member, BTS Pulmonary Rehabilitation Advisory Group; Member, the Association of Chartered Physiotherapists in Respiratory Care
- Louise Cowell, Respiratory Physiotherapy Advanced Clinical Practitioner, Warrington and Halton Teaching Hospitals
- Dr Sharada Gudur, Respiratory Medicine Consultant, Lancashire Teaching Hospitals; Previous Respiratory Champion, Asthma + Lung UK
- Dr Katherine Hickman, Respiratory Lead, West Yorkshire Integrated Care Board; Primary Care Clinical Lead, NRAP; Executive Member, Primary Care Respiratory Society
- Paul McCallion, Long-term Conditions Champion, the Association of Chartered Physiotherapists in Respiratory Care; Specialist Physiotherapist Respiratory Medicine, Newcastle Upon Tyne Hospitals
- Bradley Price, Director of Policy, Research and Involvement, Action on Pulmonary Fibrosis
- Ravijyot Saggu, Respiratory Pharmacist; Chair, United Kingdom Clinical Pharmacy Association Respiratory Committee

Finally, we would like to thank the people living with bronchiectasis who provided quotes to this policy brief to help demonstrate the impact this condition has on their lives.

Forewords

For too long, and despite affecting hundreds of thousands of people across the UK, bronchiectasis has been a hidden lung condition with a profound impact. People living with bronchiectasis often face relentless symptoms that demand intensive daily management and shape their every experience: work, relationships, sleep, mental health. People describe years of struggling to be heard. Of living with constant anxiety about the next flare-up. Of feeling invisible and isolated by a condition that most people have never heard of and that the health system has too often failed to prioritise.

At Asthma + Lung UK, we hear these stories first hand. Across the UK, committed clinical teams are working tirelessly to provide high-quality care for people with bronchiectasis, often with limited funding and a workforce under growing strain. This pressure makes the shortcomings of the current system impossible to ignore. When diagnosis is delayed, a person's lungs

can sustain damage that didn't need to happen. When specialist services are not evenly distributed, access to physiotherapy, equipment and specialist input for people with bronchiectasis depends on where they live rather than what they need. People are being let down by a system that has not properly considered this condition and the people living with it every day. This is not acceptable.

This policy brief is a much-needed resource that sets out a clear and credible path to something better. Improved awareness. Consistent, person-centred services. Stronger data and accountability. These aren't abstract policy ambitions, they are changes that would make a tangible difference to daily life for people with bronchiectasis. Achieving them will require all of us to play our part. Patient organisations, policymakers and healthcare professionals must work together with real commitment. People living with bronchiectasis in the UK have waited long enough.

Sarah Sleet
CEO, Asthma + Lung UK



Although bronchiectasis is a common, serious and lifelong respiratory condition, it continues to sit at the margins of respiratory policy and service planning. Too many people remain undiagnosed for prolonged periods, and too many of those who have a diagnosis do not receive best-practice care. The result is wide and unwarranted variation in outcomes, with patients' experiences often determined by where they live rather than by clinical need.

Delays in diagnosis are worryingly common. People with bronchiectasis frequently endure years of chronic cough, recurrent lower respiratory tract infections and repeated courses of antibiotics. By the time appropriate imaging and referral occur, the disease may be advanced.

In addition, access to specialist multidisciplinary services is highly variable, workforce pressures are

substantial, and commissioning arrangements often lack clarity. As a consequence, proven interventions are not delivered uniformly, and guideline-recommended standards are not met consistently.

Improving bronchiectasis care is both achievable and necessary; it also aligns with NHS England's *10 Year Health Plan*'s pillars of earlier intervention and care in the community. This briefing sets out a clear and timely case for action, and provides a practical framework for policymakers, commissioners and clinicians to address long-standing gaps in diagnosis, workforce capacity and service provision.

By acting decisively, we can achieve measurable progress and provide a better quality of life for people living with bronchiectasis.

Prof. Anthony De Soyza
Chair, Bronchiectasis Policy Network UK



Executive summary

Bronchiectasis is a common and serious lung condition that can have a severe, life-altering impact on the people affected. It is a condition that gets worse over time.¹ It causes inflammation that leads to irreversible widening and thickening of the airways.¹² The damage that bronchiectasis inflicts on people means they can struggle with overwhelming symptoms such as a chronic cough and repeated chest infections, which can lead to flare-ups.^{2,3} These symptoms can disrupt all aspect of a person's life, including their sleep, exercise, work and their relationships with others. Additionally, many people – especially those who have severe symptoms and need regular treatment in hospital – can experience anxiety or depression.⁴⁻⁶

Many people with bronchiectasis struggle to receive the care they need due to unacceptable delays in receiving a diagnosis and few treatment options. People with bronchiectasis often have to wait many years for an accurate diagnosis. Data from the UK suggest that people often wait between one and two years to receive an accurate diagnosis.^{7,8} However, recent European data indicate that over 25% of people with bronchiectasis experience symptoms for over ten years before receiving an accurate diagnosis.⁹ During this time, many people are incorrectly diagnosed with more common conditions, such as asthma and chronic obstructive pulmonary disease (COPD), and consequently provided with ineffective treatments.^{10,11} Current guideline-recommended care relies largely on managing symptoms; this involves, for example, regular antibiotics and physical clearance of the airways, which can place a huge burden on people living with the condition.¹²

Box 1. Bronchiectasis is a growing clinical and economic challenge

Around 340,000 people were living with bronchiectasis in the UK in 2013 (the latest year for which data are available for the whole UK).^{19,20} However, this figure is likely an underestimation due to the condition commonly being misdiagnosed; data from 2018 suggest there could be over 200,000 people living with bronchiectasis in England alone.^{21,22}

The number of deaths caused by bronchiectasis is rising; the condition was responsible for almost 2,000 deaths in England and Wales in 2023, an increase of 40% since 2013.²³

The condition places a significant and escalating burden on the NHS, costing an estimated £1.22 billion annually, with emergency hospital admissions in England alone costing almost £36m.^{24,25}

The health system is failing people with bronchiectasis. With no NHS blueprint or specialised commissioning, bronchiectasis services are inconsistent and many regions lack essential specialist and multidisciplinary expertise (*Box 1*).^{13,14} This means that many people can be forced to travel long distances to access specialist care.^{15,16} The absence of dedicated funding for bronchiectasis has resulted in under-investment and unclear reimbursement pathways, yielding gaps in access to vital treatments and devices – such as respiratory physiotherapy and oscillating positive expiratory pressure (OPEP) devices – with some people paying out of pocket or going without.^{14,17,18}

At a time when the UK health system is already stretched and the NHS in England is undergoing major organisational shifts, bronchiectasis cannot remain an afterthought. System leaders and policymakers have a responsibility to ensure that all people with bronchiectasis, regardless of where in the UK they live, can access the care and support they need. This policy brief provides recommendations for how this can be achieved.

NATIONAL POLICY- AND DECISION-MAKERS

- **Department of Health and Social Care and NHS England:** work with the Taskforce for Lung Health to establish a modern service framework for respiratory conditions that includes bronchiectasis and sets out standards to support the delivery of consistent, high-quality, digitally enabled care – regardless of where people live.
- **Department of Health and Social Care and NHS in England, Wales, Scotland and Northern Ireland:** develop and implement a comprehensive national bronchiectasis pathway that includes assessment of non-specific respiratory symptoms to speed up the diagnosis of bronchiectasis and other respiratory conditions, and facilitate access to best-practice care for optimal disease management.
- **NHS England and NHS Wales:** develop a national service specification for bronchiectasis that aligns with existing national guidelines and provides dedicated funding to support these services in the long term to ensure all people with bronchiectasis receive best-practice multidisciplinary care.
- **NHS England, Office for Life Sciences, health innovation networks:** include bronchiectasis in the Respiratory Transformation Partnership to improve equitable access to community care and evidence-based therapies.
- **NHS in England, Wales, Scotland and Northern Ireland:** implement system-level financial incentives in primary care to drive improved primary care coding, strengthen bronchiectasis services and enhance data collection on the quality of care.
- **National Institute for Health and Care Excellence (NICE) and Scottish Intercollegiate Guidelines Network (SIGN):** commission a comprehensive bronchiectasis clinical guideline that includes clear standards of care from suspicion to diagnosis and ongoing management, and redirect to it from other respiratory guidelines, to ensure all people living with chronic respiratory diseases receive an accurate diagnosis and effective management.
- **NHS England:** update the protocols for lung cancer screening so that all incidental findings of bronchiectasis, regardless of severity, are reported to the person's general practitioner (GP), and audit how reporting is conducted nationally.
- **National Institute of Health and Care Research:** fund national- and regional-level research into the true scale of bronchiectasis, its impact on quality of life, work, education, productivity and inequalities, and how different models of care could improve health outcomes.
- **Department of Health and Social Care and NHS England:** provide additional funding to the Healthcare Quality Improvement Partnership to facilitate the inclusion of bronchiectasis in the National Respiratory Audit Programme (NRAP). NRAP should work with the British Thoracic Society on aligning matched audit metrics to enable long-term monitoring of care quality and outcomes, and the benchmarking of bronchiectasis management against other chronic respiratory conditions.

INTEGRATED CARE BOARDS (ICBs) AND HEALTH BOARDS

- Include bronchiectasis within local respiratory strategies to underpin improvements in care and consider opportunities to deliver this care through localised care pathways and innovative hub-and-spoke models to provide specialist support closer to home.
- Engage with primary care providers to review patient records and identify people with bronchiectasis who may be undiagnosed or misdiagnosed, leveraging digital and AI tools where appropriate.

PATIENT ADVOCACY ORGANISATIONS

- Deliver public awareness campaigns to reduce stigma and help people who are struggling with symptoms (but have not yet been diagnosed) to consider the condition so they can speak to a healthcare professional.
- Provide people living with bronchiectasis with information about their condition from the point of diagnosis, including how they can best manage symptoms and what guideline-compliant care should look like, using resources from Asthma + Lung UK and other patient support organisations.

PROFESSIONAL SOCIETIES*

- Improve awareness of bronchiectasis among healthcare professionals across primary and secondary care through education and practical resources.

* Including: Association of Chartered Physiotherapists in Respiratory Care, Association of Respiratory Nurses, Association for Respiratory Technology & Physiology, British Paediatric Respiratory Society, British Society for Immunology, British Thoracic Society, Microbiology Society, Primary Care Respiratory Society, Royal College of General Practitioners, Royal College of Pharmacy, Royal College of Physicians, Royal College of Radiologists, UK Clinical Pharmacy Association.

A spotlight on bronchiectasis

[†]Pronounced
'brong·kee-EK·tuh·siss'

Bronchiectasis[†] is a serious and sometimes life-threatening condition. Bronchiectasis widens and thickens the walls of a person's airways. This permanent damage leaves their lungs vulnerable to repeated infection and can trigger a cycle of persistent coughing, breathlessness and overwhelming fatigue (*Box 2*).^{1,3,8} The condition is characterised by repeated flare-ups (periods when symptoms get worse), often triggered by chest infections. Flare-ups can cause further damage to the lungs, which ultimately increases someone's risk of dying.²⁶ People with bronchiectasis who experience frequent flare-ups are twice as likely to die as those who do not.²⁶

Box 2. Bronchiectasis symptoms

Symptoms of bronchiectasis can include:^{1-3,8}

- repeated chest infections
- chest pain
- coughing up blood and/or thick, often discoloured mucus
- low mood
- tiredness
- unintentional weight loss.

The symptoms of bronchiectasis can place a heavy toll on people living with the condition, as they affect every aspect of their life. Bronchiectasis can disrupt sleep, limit movement and make even simple activities, such as walking or climbing stairs, feel exhausting.⁴⁻⁶ While bronchiectasis is often considered a condition that primarily affects older people, it can occur in people of all ages, frequently affecting work and education; some people are forced to cut back their hours or leave their jobs altogether, while young people can be unable to attend school.^{27,28} The emotional burden is equally heavy. Managing the symptoms of bronchiectasis can severely impact quality of life, cause embarrassment and result in people having to change how they live their lives.²⁹ Living with a chronic cough, unpredictable flare-ups and frequent hospital visits also leaves many people feeling anxious or depressed. This is especially true for those with more severe disease or those who find themselves repeatedly in hospital.³⁰ In the UK, between 20% and 40% of people living with bronchiectasis require hospital treatment for at least one severe flare-up per year. More than 40% of people have three or more flare-ups per year – among the highest levels in Europe.³¹

More than
40%
of people have **three or more flare-ups** per year.

20–40%
are hospitalised with
at least **one severe flare-up** per year in the UK.

I keep getting flare-ups and not being very well. I quite often hide from my family when I'm feeling really poorly. The chest pain that you get feels as if there's somebody actually standing on your chest and crushing, crushing your chest.

Shirley Harwood, Trustee for NTM Patient Care and person living with bronchiectasis

Care of people with bronchiectasis relies solely on managing symptoms. Current guideline-recommended care for bronchiectasis focuses on controlling its symptoms – leaving people with the condition to shoulder a lifelong burden.¹² People often have to rely on repeated courses of antibiotics for chest infections, even though frequent or long-term use increases their risk of antibiotic resistance.¹² Many also depend on equipment such as an OPEP device[†] to help clear the chest, medicines to thin mucus, or structured pulmonary rehabilitation to keep their symptoms in check. For some people, surgery removing small parts of their lungs becomes necessary.³² In the most severe cases, the only remaining option is a lung transplant.^{16 32}

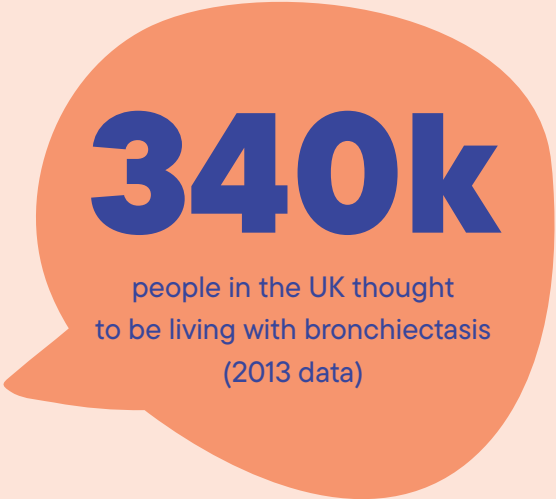
The success of bronchiectasis management relies heavily on people's ability to master complex daily routines while learning to recognise early signs of a flare-up. Many people must carry out intensive respiratory physiotherapy every day to clear their airways and allow them to breathe more easily.¹² Effective management requires people to become experts in their own illness and be constantly vigilant and engaged in self-management – often without the emotional or practical support they need.¹⁶

[†] An OPEP device is used by people living with chronic lung conditions to help their airways to stay open and clear thick mucus.³³

An escalating health and economic challenge in the UK

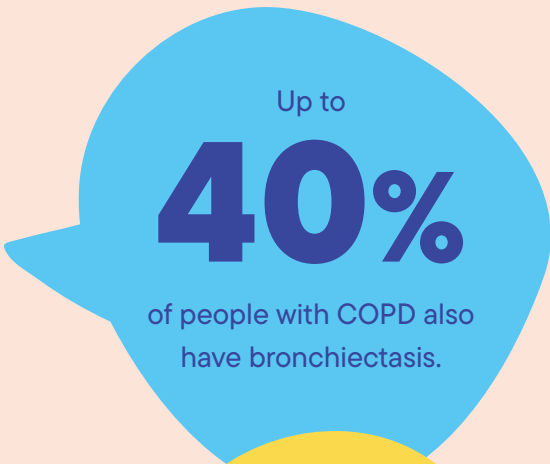
The scale and impact of bronchiectasis in the UK is considerable and growing.

Although many people have not heard of bronchiectasis, in 2013 (the most recent year for which UK-wide data are available), around 340,000 people were thought to be living with the condition.^{19 20 34} This is far greater than the number of people with more widely recognised conditions, such as cystic fibrosis or Parkinson's disease.^{35 36} The number of people living with bronchiectasis is likely to be greater still, as people are commonly misdiagnosed with conditions such as asthma or COPD; data from 2018 suggest there could be over 200,000 people living with bronchiectasis in England alone.^{21 22} People may also have bronchiectasis alongside asthma and COPD.^{37 38} Up to 40% of people with COPD also have bronchiectasis,³⁹ meaning that around 1.6 million people in the UK may be living with this complex overlap.³⁵ High rates of misdiagnosis and overlap with other respiratory conditions suggest that bronchiectasis may in fact be far more common than currently recognised – potentially making it the third most common chronic respiratory disease globally.⁴⁰ In 2023, bronchiectasis was responsible for almost 2,000 deaths in England and Wales, an increase of over 40% compared with a decade earlier.²³



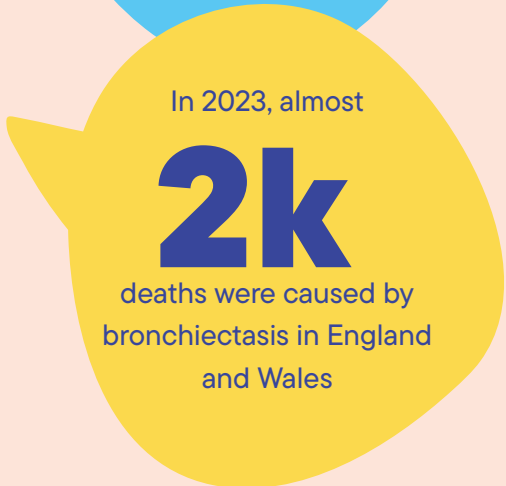
340k

people in the UK thought
to be living with bronchiectasis
(2013 data)



Up to
40%

of people with COPD also
have bronchiectasis.



In 2023, almost

2k

deaths were caused by
bronchiectasis in England
and Wales

Bronchiectasis places a heavy and escalating financial burden on the UK health system.

The need for frequent emergency care means that bronchiectasis is responsible for a disproportionate amount of healthcare spending compared with other respiratory conditions such as COPD. Every year in the UK, bronchiectasis accounts for

at least 8,500 emergency hospital admissions and a total healthcare cost in the region of £1.2 billion (Table 1).^{24 25} By comparison, COPD – which affects over 11 times as many people – is responsible for around 122,000 emergency hospital admissions and healthcare costs of £1.9 billion.^{25 35 41 42}

Table 1. Bronchiectasis in the UK

Indicator	England	Scotland	Wales
Emergency admissions per year	8,580 (2024/25) ²⁵	Data not identified	409 (2023/24) ⁴³
Readmissions per year	26,485 (30-day, 2024/25) ²⁵	Data not identified	Data not identified
Emergency admissions cost per year	£36m (2024/25) ²⁵	Data not identified	Data not identified
Number of deaths per year	1,904 (2023) ²³	207 (2008–12) ⁴⁴ Men only; data not identified for women	118 (2023) ²³

Note: there do not appear to be any specific data for bronchiectasis in Northern Ireland.



How policymakers and health system leaders can transform bronchiectasis care

IMPROVED KNOWLEDGE OF BRONCHIECTASIS IN PRIMARY CARE

Gaps in awareness of bronchiectasis among some healthcare professionals are impeding effective diagnosis and contributing to inappropriate care. GPs are usually responsible for referring people with suspected bronchiectasis for the tests needed to confirm a diagnosis. Many GPs, however, may not have the knowledge, or awareness of resources or guidance, to suspect bronchiectasis, meaning an accurate diagnosis can be delayed for many years.^{10 11 45–47} While data from the UK suggest that people often wait between one and two years to receive an accurate diagnosis,^{7 8} European data indicate that more than a quarter of people experience symptoms for over ten years before diagnosis.⁹ Over this time frame, recurrent chest infections may be repeatedly treated with antibiotics without the underlying condition being recognised – delaying appropriate care and potentially contributing to antibiotic resistance.^{48 49} Steroids may be unnecessarily prescribed for people misdiagnosed with asthma or COPD; this medication can cause significant side effects and does nothing to improve bronchiectasis.^{10 11 50} Short of intervention by a respiratory specialist, a correct diagnosis of bronchiectasis may never be achieved.⁵¹

I'd been going all the while with this cough for 20 years – they said asthma, COPD, everything barring going to see somebody who knew what they were talking about.

Person living with bronchiectasis



Addressing gaps in knowledge of bronchiectasis in primary care requires:

- **Strengthening education and guidance for primary care professionals.** Healthcare professionals need clear, practical education and resources on when to suspect bronchiectasis and how to manage it. Medical schools and professional societies must ensure bronchiectasis is comprehensively covered in their curricula and continuing professional development materials. This could, for example, be integrated into existing education programmes and materials for asthma and COPD. Existing accredited resources from the Primary Care Respiratory Society, Asthma + Lung UK and Respiratory Futures should be embedded into training – and supported by protected learning time – to improve confidence and consistency of care.^{52 53}
- **Proactively reviewing patient records for undiagnosed bronchiectasis.** Systematically reviewing medical records for repeated antibiotic use for chest infections could identify people with bronchiectasis who may be misdiagnosed or undiagnosed. Digital and AI tools could be used to support identification, while decision-support tools within primary care can also aid healthcare professionals in recognising symptom clusters, especially in people who have been misdiagnosed with asthma or COPD.



A CLEAR, STANDARDISED DIAGNOSTIC PATHWAY

Variations in referral pathways to diagnostic tools are causing serious and avoidable delays. When primary care professionals suspect bronchiectasis, people should be referred to a respiratory specialist in secondary care.⁵⁴ However, the route from suspicion to diagnosis is far from consistent. Some people may receive critical investigations such as computed tomography (CT) scans (the main diagnostic tool for bronchiectasis), immunological testing and microbiology testing while awaiting referral.⁵⁵ Other people must first undergo a series of preliminary tests – such as blood tests, spirometry or chest X-rays – before being considered eligible for a CT scan, further complicating and prolonging the diagnostic process.⁶

Eventually, I said to the GP, ‘Don’t you think I should have a CT scan because this just isn’t going away, it’s really a nuisance’.

Person living with bronchiectasis



Structural barriers lead to further delays in diagnosis. The key diagnostic tests are not widely available and access varies by region.^{48 50} Restricted access to CT scanners from primary care, a national shortage of scanners and significant workforce shortages in radiology all contribute to extended time frames to diagnosis.^{13 56 57} By the time some people are finally diagnosed, they may be too ill for symptom management to be effective.⁵⁸ Although some areas of England now benefit from quicker access to diagnostic tests through community diagnostic centres, provision is far from universal.⁵⁹ Despite repeated commitments from the UK government to expand these centres, they remain unevenly distributed, creating a postcode lottery that continues to determine how quickly people with bronchiectasis receive a diagnosis and appropriate care.^{6 11 60}

The absence of a clear, comprehensive clinical guideline that spans both primary and specialist care has led to major inconsistencies in how bronchiectasis is diagnosed and managed across the UK. The British Thoracic Society has produced detailed guidelines for bronchiectasis.¹² However, the complexity of these guidelines – combined with multiple, sometimes overlapping recommendations from different sources – makes it difficult for many healthcare professionals in primary care to retain and understand key recommendations and apply them in practice.^{48 54 61 62} Similarly, resources that primary care teams rely on, including the clinical knowledge summaries from NICE, are specific to one condition.⁵⁴ This poses a challenge when someone presents with non-specific symptoms, such as cough or breathlessness, which could signal a number of respiratory conditions.^{54 61} This lack of clarity can lead to delayed referral and inconsistent treatment even after symptoms are recognised. For example, many GPs do not follow the recommended 14-day course of antibiotics for bronchiectasis flare-ups, often due to confusion about how this aligns with antibiotic stewardship policies.^{10 12 13} Consequently, people with bronchiectasis may receive shorter courses that fail to address infection effectively, risking further lung damage and increased antibiotic resistance.

Reporting and referral guidelines for bronchiectasis from lung cancer screening are incomplete and do not align with national diagnostic ambitions. Bronchiectasis can be identified during screening for lung cancer. However, national guidance for lung cancer screening recommends reporting to a person's GP and referring to a respiratory service only where moderate to severe bronchiectasis is visible in a scan, but not when it is mild.⁶³ This overlooks early bronchiectasis as a condition that can already cause symptoms and may get worse. The guidance also fails to align with national action plans, such as the *10 Year Health Plan for England* and the *Scottish Respiratory Care Action Plan*, which include objectives that focus on prevention and early diagnosis rather than the management of late-stage disease.^{64 65}

I didn't know why I wasn't referred to the bronchiectasis clinic. I think everyone with bronchiectasis should be referred to a bronchiectasis specialist.

Person living with bronchiectasis

Improving accurate and timely diagnosis will require the development of relevant pathways and guidance to support effective bronchiectasis identification and referral.

- **Develop an integrated, comprehensive and person-centred bronchiectasis care pathway.** The pathway should be developed at a national level to support suspicion and diagnosis of bronchiectasis in people of all ages, based on non-specific symptoms such as a persistent productive cough, and to improve referral to the appropriate disease-specific pathway. It could include a structured consultation and clinical template, and be supported by GP system flags for repeat antibiotic use to prompt earlier referrals and imaging.
- **Require ICBs and health boards to include bronchiectasis in local respiratory strategies.** Local respiratory strategies based on consistent national standards are needed. These would set out clear referral pathways, robust plans for timely diagnosis, and consistent expectations for service delivery that are tailored to the local context. These strategies should also outline how local systems will make full use of regional community diagnostic centres – where available – that have adequate capacity for CT scanners, to improve patient access to investigations.
- **Develop comprehensive NICE and SIGN guidelines for bronchiectasis.** New, detailed NICE and SIGN guidelines with clear diagnostic algorithms, escalation steps and standards of care would streamline decision-making in primary and secondary care. Guidelines for other respiratory conditions should include prompts to investigate bronchiectasis when a person experiences two or more chest infection-related antibiotic courses within 12 months.
- **Update lung cancer screening reporting protocols and audit report outcomes.** These national standards developed by NHS England should recommend reporting all bronchiectasis findings to GPs, to enable earlier diagnosis. To support consistent implementation, screening programmes should include routine auditing of radiology reports against reporting standards and clear local pathways for acting on scan findings. The pathways should be accompanied by guidance for healthcare professionals in primary care on management, referral and escalation to respiratory specialists.

CONSISTENT DELIVERY OF MULTIDISCIPLINARY BRONCHIECTASIS CARE

The absence of a national, NHS-endorsed blueprint for specialist bronchiectasis services has created fragmented and inequitable care across the UK. Few hospitals are able to offer best-practice 'one-stop' bronchiectasis clinics supported by multidisciplinary teams that include specialist respiratory consultants, nurses, physiotherapists, radiologists, immunologists, pharmacists and microbiologists.¹³⁻¹⁵ And there is no overarching guidance to support or mandate this level of care.⁶¹ In some regions, the gaps are so significant that respiratory physiotherapists from other areas are required to fill the void, often without proper reimbursement for the additional workload.^{14 66} This is neither sustainable nor equitable, and it highlights a system relying on temporary fixes instead of providing the coordinated, well-resourced specialist services that people with bronchiectasis urgently need.

The lack of national standards means access to essential specialist physiotherapy is widely uneven. Pulmonary rehabilitation (Box 3) and respiratory physiotherapy (Box 4) are the cornerstones of bronchiectasis management.⁶⁷ Yet, regional data reveal a stark reality: less than 30% of people with bronchiectasis receive a referral to respiratory physiotherapy. It is the same grim picture for pulmonary rehabilitation.^{66 68} These gaps in access leave people with bronchiectasis vulnerable to frequent chest infections and increasingly reliant on antibiotics, driving up costs and accelerating antibiotic resistance and other side effects.⁴⁸

Box 3. Pulmonary rehabilitation

Pulmonary rehabilitation is recommended in bronchiectasis guidelines as integral to the management of symptoms. It comprises individualised exercise training and education, delivered by a multidisciplinary team.⁶⁹ This approach can improve the ability of people with bronchiectasis to exercise and their quality of life.^{12 69 70}

Box 4. Respiratory physiotherapy and airway clearance training

Respiratory physiotherapy for bronchiectasis involves educating people with the condition on effective airway clearance techniques. This helps people remove mucus that would otherwise accumulate in the lungs.⁷¹ These techniques can reduce the risk of chest infections, enhance quality of life, and equip people with the confidence and skills needed to self-manage their condition.^{61 71 72}



The physiotherapist gave me advice on self-management, how not to cough, and they were very, very good. [I got advice on] breathing exercises as well.

Person living with bronchiectasis

Uneven access to bronchiectasis-specific respiratory specialists is driving unacceptable inequalities. For many people, travelling to the nearest specialist service can be overwhelming. Individuals may face long, costly and exhausting journeys – an especially heavy burden for those already very unwell, living in poverty, with caring responsibilities, or unable to take time off work to attend appointments.^{15 16} Clinics based in Newcastle, for example, will routinely see people from as far as York, Cumbria and the Scottish Borders – distances of around 80 miles.^{15 61} In Wales, people living in rural areas may face particularly long journeys to receive specialist care.⁴⁵ Other chronic respiratory conditions, such as COPD and severe asthma, can be treated in hub-and-spoke services that increase access to specialist care in the community and effective interventions, and reduce travel requirements.^{73 74} Without similar innovative models of care in place for bronchiectasis, people with the condition and their families face physical and financial strain, and disparities in health outcomes are likely exacerbated.

I do wish I had been allowed to access further care without having to sort of fight it out.

Person living with bronchiectasis



Bronchiectasis is systematically marginalised within national respiratory strategies and policies, perpetuating inequitable access to specialist care and underscoring the urgent need for formal policy recognition and dedicated commissioning.

Many chronic respiratory diseases, including severe asthma, interstitial lung disease and pulmonary hypertension, hold specialised commissioning status, which means these specialist services receive direct national funding (*Appendix 1*).^{75 76} This status is not available for bronchiectasis, however, meaning there is no dedicated funding for specialist bronchiectasis services. Ultimately, this leads to a patchwork of care provision. Some regions prioritise clinics for respiratory diseases that receive direct funding, while bronchiectasis services remain under-resourced and inconsistently staffed.¹⁴ In some areas where specialist bronchiectasis services are not available, healthcare professionals may purposely mis-record people with bronchiectasis as having COPD so that they qualify for pulmonary rehabilitation (which otherwise they may not receive).⁵⁰ Bronchiectasis has also not been included in the cross-sector Respiratory Transformation Partnership initiative, which is driving whole pathway transformation in asthma and COPD care through workstreams that aim to diagnose asthma and COPD in the community and provide more equitable access to innovative medicines.⁷⁷ Respiratory conditions are not currently included in the plans for modern service frameworks (MSFs), which are being trialled by the NHS in England with the aim of improving the delivery of digitally led, high-quality, evidence-based care (*Appendix 2*).⁷⁸

Funding restrictions limit access to OPEP

devices. Access to OPEP devices can be a real challenge for people in regions where there is no clear mechanism for reimbursement.^{17 18} This is in contrast to peak-flow devices for asthma, which are widely prescribed on the NHS.⁷⁹ Ambiguity around reimbursement can result in disagreements between primary and secondary care regarding who is responsible for funding OPEP devices, potentially leaving people with bronchiectasis without access unless they can pay for the device themselves.¹⁸

Tackling the variable and limited access to specialist services will require the development of centralised funding and forward-thinking approaches to service delivery.

- **Develop a centrally funded national service specification to support widespread access to multidisciplinary teams.** National service specifications define the standards of care expected from specialised service providers funded by the NHS in England and Wales. A service specification for bronchiectasis that aligns with national guidelines would transform access to specialist care by ensuring availability of fully equipped multidisciplinary teams with the resources to deliver consistent, high-quality care that includes OPEP devices. Centralised funding would support long-term sustainability, reduce variation between regions, and ensure that specialist support is available in primary and community care – not just in a handful of well-resourced hospitals.
- **Develop an MSF for respiratory care.** An MSF for respiratory conditions including bronchiectasis is urgently needed and the Taskforce for Lung Health is developing a blueprint off which the MSF could be based.⁸⁰ The MSF could help to standardise referral pathways and guarantee equitable access to multidisciplinary care across all regions. Clear service requirements, defined staffing and capacity standards, and robust accountability mechanisms would help ensure health systems can deliver timely, effective care while alleviating wider system pressures. Bronchiectasis could also act as a compelling example for the delivery of the NHS *10 Year Health Plan*, which establishes the role of MSFs. The condition is well suited to testing system-wide ambitions to shift care from hospital to community settings, upskilling patients and primary care teams, improving early identification, and moving from reactive treatment to prevention.
- **Include bronchiectasis in the Respiratory Transformation Partnership.** Adding bronchiectasis to this programme of work would establish dedicated workstreams that can drive more equitable access to care in the community and could support provision of evidence-based therapies such as pulmonary rehabilitation and respiratory physiotherapy.
- **Expand hub-and-spoke approaches to improve access to specialist bronchiectasis services.** Local system leaders must embrace innovative approaches to care, such as hub-and-spoke models with virtually enabled outreach. These models can connect regional specialist centres with district hospitals to strengthen bronchiectasis management, particularly respiratory physiotherapy, and address regional inequalities. To be effective, these models require protected clinical time, appropriate workforce resourcing, and fair reimbursement for the additional expertise provided across sites.

GREATER PUBLIC AWARENESS

Public awareness of bronchiectasis appears to be consistently low, contributing to delays in diagnosis and limiting effective management.

Almost 70% of people diagnosed with bronchiectasis had not previously heard of the condition.⁷ This lack of awareness may mean that people accept symptoms as 'normal' and therefore do not seek help, consequently missing critical opportunities for timely diagnosis and treatment. Even after diagnosis, if people do not receive the right guidance or resources from their healthcare team, they may be unclear on how to effectively manage their condition, which can result in repeated flare-ups and worsening symptoms.⁸¹ Resources such as Asthma + Lung UK's 'patient passport' and self-management plan can help, but these need to be actively promoted by healthcare professionals.^{82 83} The benefits are wide ranging, as stronger self-management support can reduce reliance on primary care and improve symptom control.^{10 11 45} Additionally, while there are currently no approved smartphone apps to support people in managing their bronchiectasis symptoms, technology is being successfully implemented in other respiratory diseases, with eight digital platforms recommended by NICE for asthma.⁸⁴

Widespread misunderstanding means many people living with bronchiectasis persistently fear being judged, intensifying the psychological burden of their disease.

The hallmark symptoms of bronchiectasis, particularly chronic coughing that produces mucus, are widely misunderstood. Since the COVID-19 pandemic, these symptoms are frequently perceived by others as signs of an infectious illness. They may also be incorrectly attributed to smoking, despite smoking not being a primary cause of bronchiectasis.^{14 50 66} These misconceptions fuel stigma, cause discomfort, judgement or avoidance from others.^{6 66}

Even if you have no sputum, the cough itself makes people nervous. And it's more nowadays, since COVID. So they all say 'that person is coughing. I don't want to sit next to them'.

Marion Wilkens, President of Alpha1 Germany and person living with bronchiectasis



Addressing the gap in public understanding of bronchiectasis will require targeted information-sharing to reduce stigma, support the social and emotional wellbeing of people with bronchiectasis, and improve self-management.

- **Launch targeted public awareness campaigns to improve knowledge of bronchiectasis, reduce stigma and encourage people to seek help sooner.** Well-designed public awareness campaigns, delivered by patient advocacy organisations, could encourage people with persistent respiratory symptoms to seek help earlier. Increasing public understanding could also reduce stigma around symptoms such as chronic coughing.
- **Empower people with bronchiectasis by supporting them to understand the care they should expect from the point of diagnosis, and by providing resources so they can better manage their symptoms and rely less on healthcare services.** People with bronchiectasis need accessible, reliable information on how to manage their condition and on the care they should expect to receive. Digital tools such as smartphone apps could further transform bronchiectasis self-management.

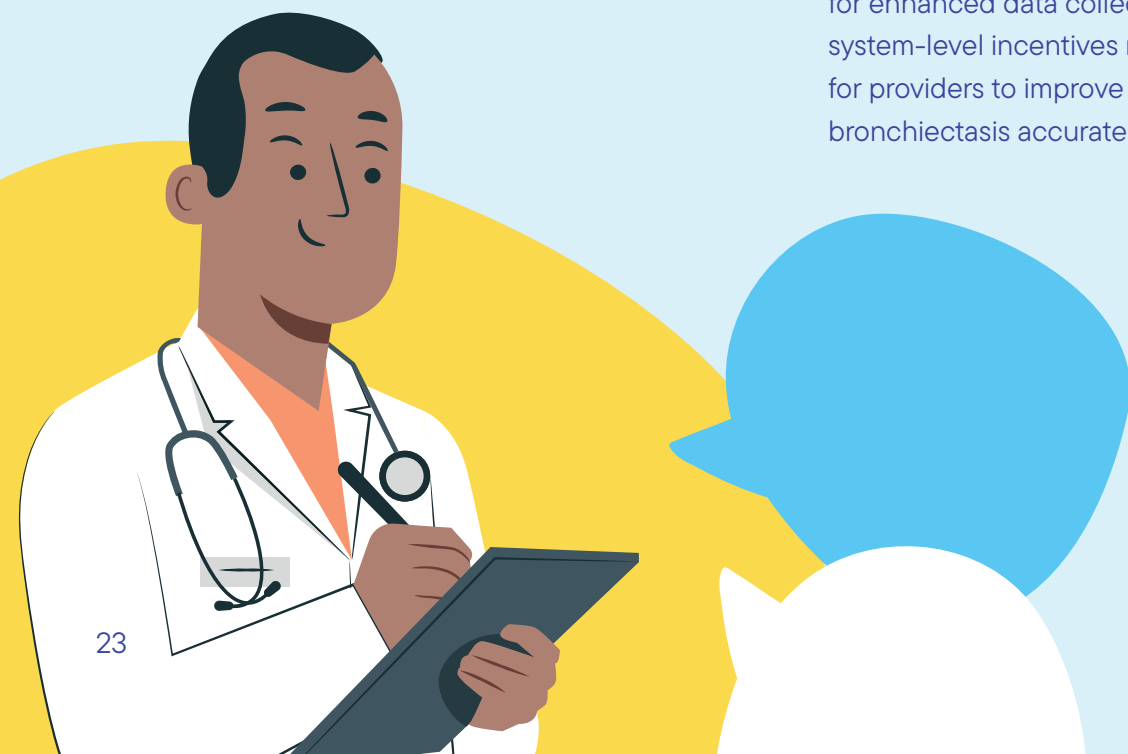


EXPAND BRONCHIECTASIS DATA COLLECTION AND FINANCIAL INCENTIVES

Robust, reliable data on bronchiectasis care are severely lacking, making it difficult for policymakers, commissioners and health system leaders to understand the true scale of impact and need. Routinely collected primary care data for bronchiectasis are widely considered poor quality because people with bronchiectasis are frequently miscoded as having asthma or COPD.^{15 85 86} This undermines prevalence estimates, limits the usefulness of data for research, and obscures the real impact of the disease. Secondary care data are similarly outdated. The last national audit by the British Thoracic Society took place in 2017, leaving healthcare professionals and decision-makers without recent insight into how bronchiectasis is currently being diagnosed and managed.¹² At the system level, key indicators such as waiting times, hospital length of stay, rates of exacerbation, patient-reported outcome and experience measures as well as the cost and frequency of antibiotic use are not routinely collected, and there are no time trend dashboards.⁶¹ This lack of visibility makes it nearly impossible to identify unwarranted variation or design services that meet people's needs.^{18 66 87}

The wider societal impact of bronchiectasis is also poorly understood. People with bronchiectasis may be less able to study or work, need to reduce their work hours, or leave employment earlier than they would have done if their condition were well managed.^{27 28} But these economic costs are rarely captured. Similarly, many factors known to influence prevalence and flare-up risk – such as deprivation, air pollution, damp housing and occupational exposure – are not systematically monitored in relation to bronchiectasis. This data deficit leaves health system planners in the UK without a full picture of the impact bronchiectasis has on health, society, finances and the economy, contributing to its low prioritisation in national policy.^{18 66}

Financial incentives to improve bronchiectasis outcomes, care and data collection remain limited. COPD and asthma benefit from dedicated financial incentives, national targets, routine data collection and auditing through programmes such as Core20PLUS5, the NRAP and the quality and outcomes framework (QOF) in England.⁸⁸⁻⁹⁰ But bronchiectasis is absent from these initiatives. This reinforces the low profile of the disease, despite its substantial clinical consequences and economic costs for both individuals and the health system. Other programmes that support improvements in population health, such as the Investment And Impact Fund (IIF) from NHS England and the QOF in Wales, do not include any indicators for respiratory conditions, further limiting opportunities for enhanced data collection.⁹¹⁻⁹³ This lack of system-level incentives means there is little impetus for providers to improve outcomes and record bronchiectasis accurately or consistently.



Improving bronchiectasis services will require more accurate and systematic data collection and financial incentives.

- **Strengthen data collection and utilisation.**

National and local-level investment in research that links existing data-sets is needed to better understand the impact of bronchiectasis on quality of life, work, education and productivity. This should include key diagnostic and management metrics such as time to diagnosis, exacerbation and referral rates, and adherence to guideline-recommended antibiotic prescribing. Strengthening the evidence base in this way would help policymakers understand the broader financial and societal costs of poor bronchiectasis management, as well as the impact of health inequalities.

- **Include bronchiectasis and other chronic respiratory diseases in key national incentive-based programmes such as Core20PLUS5, QOF and the IIF.**

Embedding respiratory conditions within performance-based indicators would incentivise better care and improve the accuracy of primary-care coding, which is crucial for tracking bronchiectasis prevalence, monitoring healthcare use and ensuring people access the most effective treatments. High-quality data will also be essential when the General Practice Data for Planning and Research system launches, enabling large-scale analysis of patient records and supporting research to identify patterns that could strengthen bronchiectasis diagnosis and long-term management.⁹⁴

- **Include bronchiectasis in the NRAP.**

Transitioning the national bronchiectasis audit from the British Thoracic Society into the NRAP would enable long-term monitoring of management and outcomes, including the extent to which people can access investigations and respiratory physiotherapy. Continuity of established bronchiectasis metrics would be essential for capturing time-tracked data, and the merging of these audits can leverage existing NRAP infrastructure, such as the pulmonary rehabilitation metrics. This integration would enable sustainable, long-term data tracking for bronchiectasis, facilitate direct comparisons with asthma and COPD, support mapping of specialist services and access, and generate system-wide insights to identify unwarranted variation and inequities – informing targeted investment and service improvement across the UK.

Looking ahead: a brighter future for people with bronchiectasis

Bronchiectasis has remained neglected for far too long. It is a condition marked by low policy attention, the absence of national guidelines, insufficient funding, poor public awareness and limited recognition in primary care. Current health systems in the UK lack the structured pathways, specialist services and data infrastructure needed to deliver equitable, high-quality care. As a result, too many people experience prolonged delays in diagnosis – limiting access to essential services and support, and contributing to avoidable worsening of symptoms.

The Bronchiectasis Policy Network UK has set out a clear vision for a future in which people living with bronchiectasis are supported by a coordinated and responsive health system.

Achieving this will require decisive action to advance clinical education, develop care pathways, strengthen services, improve data collection and enhance public awareness.

Taken together, these actions represent a pathway toward a more equitable and person-centred approach to bronchiectasis care – one that aligns closely with the NHS's strategic priorities for earlier diagnosis, community-based care and improved outcomes for chronic conditions. With concerted effort across the health sector, it is possible to transform the experience of people living with bronchiectasis, so they can finally receive the high-quality care they need.



NATIONAL POLICY- AND DECISION-MAKERS

- **Department of Health and Social Care and NHS England:** work with the Taskforce for Lung Health to establish a modern service framework for respiratory conditions that includes bronchiectasis and sets out standards to support the delivery of consistent, high-quality, digitally enabled care – regardless of where people live.
- **Department of Health and Social Care and NHS in England, Wales, Scotland and Northern Ireland:** develop and implement a comprehensive national bronchiectasis pathway that includes assessment of non-specific respiratory symptoms to speed up the diagnosis of bronchiectasis and other respiratory conditions, and facilitate access to best-practice care for optimal disease management.
- **NHS England and NHS Wales:** develop a national service specification for bronchiectasis that aligns with existing national guidelines and provides dedicated funding to support these services in the long term to ensure all people with bronchiectasis receive best-practice multidisciplinary care.
- **NHS England, Office for Life Sciences, health innovation networks:** include bronchiectasis in the Respiratory Transformation Partnership to improve equitable access to community care and evidence-based therapies.
- **NHS in England, Wales, Scotland and Northern Ireland:** implement system-level financial incentives in primary care to drive improved primary care coding, strengthen bronchiectasis services and enhance data collection on the quality of care.
- **NICE and SIGN:** commission a comprehensive bronchiectasis clinical guideline that includes clear standards of care from suspicion to diagnosis and ongoing management, and redirect to it from other respiratory guidelines, to ensure all people living with chronic respiratory diseases receive an accurate diagnosis and effective management.
- **NHS England:** update the protocols for lung cancer screening so that all incidental findings of bronchiectasis, regardless of severity, are reported to the person's GP, and audit how reporting is conducted nationally.
- **National Institute of Health and Care Research:** fund national- and regional-level research into the true scale of bronchiectasis, its impact on quality of life, work, education, productivity and inequalities, and how different models of care could improve health outcomes.
- **Department of Health and Social Care and NHS England:** provide additional funding to the Healthcare Quality Improvement Partnership to facilitate the inclusion of bronchiectasis in the NRAP. NRAP should work with the British Thoracic Society on aligning matched audit metrics to enable long-term monitoring of care quality and outcomes, and the benchmarking of bronchiectasis management against other chronic respiratory conditions.

ICBs AND HEALTH BOARDS

- Include bronchiectasis within local respiratory strategies to underpin improvements in care and consider opportunities to deliver this care through localised care pathways and innovative hub-and-spoke models to provide specialist support closer to home.
- Engage with primary care providers to review patient records and identify people with bronchiectasis who may be undiagnosed or misdiagnosed, leveraging digital and AI tools where appropriate.

PATIENT ADVOCACY ORGANISATIONS

- Deliver public awareness campaigns to reduce stigma and help people who are struggling with symptoms (but have not yet been diagnosed) to consider the condition so they can speak to a healthcare professional.
- Provide people living with bronchiectasis with information about their condition from the point of diagnosis, including how they can best manage symptoms and what guideline-compliant care should look like, using resources from Asthma + Lung UK and other patient support organisations.

PROFESSIONAL SOCIETIES*

- Improve awareness of bronchiectasis among healthcare professionals across primary and secondary care through education and practical resources.

* Including: Association of Chartered Physiotherapists in Respiratory Care, Association of Respiratory Nurses, Association for Respiratory Technology & Physiology, British Paediatric Respiratory Society, British Society for Immunology, British Thoracic Society, Microbiology Society, Primary Care Respiratory Society, Royal College of General Practitioners, Royal College of Pharmacy, Royal College of Physicians, Royal College of Radiologists, UK Clinical Pharmacy Association.

Appendices

1. SERVICE SPECIFICATIONS FOR SPECIALISED CARE IN ENGLAND AND WALES^{II}

Within the NHS in England and Wales, specialised services have been set up to support people with a range of rare or complex conditions. They deliver cutting-edge care and support pioneering clinical practice in the NHS, and are delivered by regional specialist teams of doctors, nurses and other healthcare professionals who have the necessary skills and experience.^{95 96}

Service specifications are developed by the NHS and clearly define the standards of care expected from organisations funded by the NHS in England and Wales to provide specialised services. They are developed by specialist clinicians, commissioners, expert patients and public health representatives, and include core standards that all funded providers should be able to deliver.^{75 97} This ensures that all organisations which deliver these services must provide a clearly defined level of service that is uniformly implemented across the country, thereby reducing regional inequalities for people living with these conditions.

2. MODERN SERVICE FRAMEWORKS FOR THE NHS IN ENGLAND

MSFs will play a central role in transforming how care is delivered in England, supporting more consistent, high-quality, evidence-based and digital-by-default pathways. These frameworks are being developed through clinically led design, with task-and-finish groups co-designing each MSF alongside healthcare professionals, people with lived experience and system partners. Early MSFs are focused on cardiovascular disease, serious mental illness and sepsis, with frameworks on dementia and frailty to follow.

MSFs will be used to fundamentally rethink care pathways, so that modern technology can empower people to manage their own care and access treatment digitally where it is clinically safe and appropriate. This shift aims to improve outcomes, enhance patient experience, free clinical capacity and support financial sustainability.^{78 98}

^{II} This example reflects the current landscape for service specification development in England and Wales. However, it should be noted that this process may change as NHS England is absorbed into the Department of Health and Social Care.

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