

Breathless for Answers:

Strengthening the Adult Breathlessness
Pathway for national rollout



Produced by



The Taskforce for Lung Health is a collaboration of the largest ever group of organisations and individuals who have come together to improve lung health in England.

The Taskforce has over 50 members including patients, carers, healthcare professionals, the voluntary sector and professional associations.

The Taskforce for Lung Health receives financial support from both pharmaceutical and med-tech companies. However, contributing companies have no editorial control over Taskforce activities, decisions, or publications. The Taskforce for Lung Health retained full editorial control over the content of this report. A full list of contributing companies in 2026 can be found at www.taskforceforlunghealth.org.uk.

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Executive summary



1 in 10 people in the UK live with chronic breathlessness, a symptom associated with poorer quality of life, functional decline, premature mortality and substantial healthcare use. Breathlessness accounts for over 4% of GP consultations and is linked to 1 in 5 emergency admissions. Despite its prevalence and impact, chronic breathlessness remains underdiagnosed and undertreated, with many people facing delays in diagnosis, fragmented care and repeated hospital admissions before receiving appropriate support.

The NHS England Adult Breathlessness Pathway was developed to address this challenge by enabling faster and more accurate diagnosis through a holistic, symptom-based approach that considers the full range of potential underlying causes, rather than focusing on individual diseases in isolation.

This report examines how the Adult Breathlessness Pathway has been implemented in practice and makes recommendations on factors which could inform greater success. Drawing on interviews with pathway leads, clinicians, commissioners and healthcare scientists across England, the report identifies both the benefits of the pathway and the barriers limiting wider rollout.



The report demonstrates that where the pathway is implemented effectively it can:

- Reduce time to diagnosis from many months to weeks.
- Deliver diagnosis at the first appointment for a significant proportion of patients.
- Improve patient experience through coordinated, one-stop diagnostic assessment.
- Reduce pressure on respiratory outpatient services by directing patients to the most appropriate care.
- Create opportunities for earlier intervention and prevention of deterioration.

However, implementation remains inconsistent. Successful services have relied heavily on local champions, personal relationships and motivated individuals. As a result, access to the pathway varies considerably across England.



Stakeholders identified several recurring barriers to implementation:

- Low prioritisation of respiratory care.
- Loss of respiratory clinical leadership within ICBs.
- Workforce shortages.
- Short-term funding arrangements.
- Lack of national implementation guidance and support.
- Low awareness and engagement within primary care.
- Fragmented digital infrastructure and poor interoperability.

Without action to address these barriers, successful implementation risks remaining dependent on individual effort rather than being embedded within system-level structures. The report sets out five recommendations to overcome these challenges and create the conditions for consistent and sustainable implementation of the pathway across England.

Recommendation 1

To the Department of Health and Social Care:

Establish respiratory care as a national priority through a Modern Service Framework, giving Integrated Care Boards (ICBs) and Trusts the mandate and support to prioritise respiratory pathways such as the Adult Breathlessness Pathway.

Recommendation 2

To NHS England, its successor bodies and Integrated Care Boards:

Mandate and protect named clinical respiratory leadership roles at ICB level, providing a permanent and structured route to senior organisational leadership and accountability.

Recommendation 3

To NHS England and its successor bodies:

Establish a national implementation and evaluation toolkit, including a national dataset and dashboard, ensuring that pathway leads have the standardised guidance, tools and resources they need to implement, evaluate and promote the pathway.

Recommendation 4

To the Department of Health and Social Care:

Deliver joined up digital infrastructure and national data standards, including implementation of the single patient record and joined up IT systems, enabling seamless information sharing and reliable data collection, evaluation and continuity of care.

Recommendation 5

To NHS England and its successor bodies:

Commit to a multi-year funding model, giving pathway leads sufficient time to recruit staff, establish the pathway, demonstrate its impact and develop a sustainable business case for long-term delivery.

Introduction

1 in 10 people in the UK suffer from chronic breathlessness, a symptom with a lasting impact on every aspect of daily life from getting washed and dressed to socialising with family and friends to simply completing daily routines.^{1,2} It leads to poorer quality of life and premature mortality, increasing the risk of physical functional decline by 40% and the risk of death by 60%.³ With over a third of adults aged 70 and older experiencing breathlessness this impact is expected to grow as the population ages.

Breathlessness is a common presenting symptom in primary care making up over 4% of GP consultations.⁴ Cardiorespiratory diseases such as chronic obstructive pulmonary disease (COPD), asthma and heart failure account for over two thirds of breathlessness symptoms with other underlying factors including obesity and mental health.^{5,6,7} This range of potential underlying causes makes the symptom difficult to diagnose and treat⁸ and traditional diagnostic pathways, developed through a disease-specific lens focused on managing individual conditions in isolation, are often poorly suited to it.

Breathlessness can also be difficult to recognise, as people may gradually adapt their lifestyles to their symptoms, while symptoms may not be apparent during clinical consultations.^{9,10} Stigma around causes such as smoking can further discourage people from seeking support. As a result, chronic breathlessness remains underdiagnosed and undertreated¹¹,

with many people not seeking help in the first place and those who do facing dismissal of symptoms, unequal access to diagnostic tests, delayed investigations and even misdiagnosis.

To address this, NHS England developed the Adult Breathlessness Pathway toolkit in 2023 supporting primary care to diagnose chronic breathlessness earlier through a symptom-based approach that considers all potential underlying causes rather than a single disease in isolation.¹² The Taskforce for Lung Health was involved in the early development of the Adult Breathlessness Pathway, providing input to help ensure it reflected the needs of people living with lung conditions. As the pathway moved from development to implementation, the Taskforce therefore sought to understand how it was working in practice, what has worked well and what was needed to support wider and more sustainable rollout.

To do this, the report draws on interviews with over 20 stakeholders involved in the development and delivery of the pathway at national and local level from ICB commissioners, healthcare scientists, respiratory and cardiology consultants, and respiratory leads. This included stakeholders that had stopped delivering the pathway, those with recently established services, and those with more established pathways, as well as clinical teams delivering breathlessness pathways outside the Community Diagnostic Centre (CDC) model. While the report focuses primarily on implementation through CDCs, it also considered pathway models delivered outside the CDC to identify lessons that could inform wider rollout.

Adult Breathlessness Pathway implementation to-date

Given the importance of fast and accurate diagnosis in reducing both the burden on patients and the NHS, the Adult Breathlessness Pathway has been prioritised within national NHS planning, including the NHS's Elective Care Plan to help meet the 18 week referral to treatment standard¹³ and the cardiovascular disease Modern Service Framework to support rapid referral, treatment and diagnosis for people with suspected heart failure.

The Adult Breathlessness Pathway was also identified as a priority for delivery through CDCs, which were established to provide faster, more accessible diagnostic testing in the community, reduce pressure on acute settings and address health inequalities.¹⁴ As of 2025, more than 170 CDCs were operating and had delivered 14.7 million tests¹⁵ with early evidence showing reduced waiting times and faster diagnosis.^{16,17}

Despite this national prioritisation, rollout of the Adult Breathlessness Pathway has been slow and its implementation remains inconsistent across England. While the pathway can deliver significant benefits for patients and the health service, stakeholders identified a range of systemic barriers to wider implementation, including funding uncertainty, limited guidance, workforce capacity, fragmented digital systems, low awareness and variable leadership support.

What emerges from the findings is that successful implementation has often depended heavily on the effort, relationships and commitment of individuals rather than system-level support. While this has demonstrated what can be achieved locally, reliance on individual leadership and local relationships makes successful models difficult to sustain and replicate at scale, contributing to variation in access to care.



The case for the pathway

Breathlessness places a significant burden on patients and the NHS

Chronic breathlessness is a significant driver of pressure on the health service, particularly emergency care. It accounts for nearly 20% of emergency admissions, while more than a third of people attending emergency care have an underlying chronic breathlessness symptom.¹⁸ This represents a substantial opportunity for earlier diagnosis and intervention, both to improve outcomes for individuals and to reduce burden on the health service.

Yet many people who attend emergency care with chronic breathlessness do not receive appropriate follow-up. Over a third are discharged without a management plan, contributing to repeated emergency admissions and persistent, unresolved symptoms.¹⁹ The estimated annual cost of breathlessness in the UK is £1.2billion with formal care costing an estimated £3,253 per patient over three months, of which hospitalisation accounts for 60%. When informal care is included, the costs rise substantially to £11,507 per patient.²⁰ These figures demonstrate the scale of the challenge and the potential benefits of improving diagnosis.



The pathway can support faster and more accurate diagnosis

The Adult Breathlessness Pathway offers an opportunity to intervene earlier in the patient's journey. Where the pathway is active it has consistently demonstrated faster diagnosis. Several pathway leads reported that around half of patients received a diagnosis at their first visit, with breathing pattern disorder (BPD), anxiety, obesity and deconditioning among the most common diagnoses. A CDC in South East England diagnosed BPD in around 60% of patients, while a CDC in West Midlands reported around 40% of diagnoses as BPD or anxiety related. Diagnosis was also faster with a CDC in East England reporting patients progressing from referral to diagnosis in around one month, compared with several months in a general respiratory clinic, while a CDC in South East England reported patients were seen within one week of referral and triage, against an average one-year wait in the general respiratory clinic. At another CDC in West Midlands, the pathway achieved 78% higher diagnosis rate than the respiratory clinic.

Delivering the pathway through CDCs has been central to achieving faster diagnosis, as CDCs provide access to a range of diagnostics tests under one roof, acting as a "one-stop shop". Stakeholders particularly valued the ability to "ring-fence time" for testing and diagnosis on the same day.

“

Patients like coming in for a single appointment... having everything done in one hit.”

– Healthcare scientist

The high proportion of non-respiratory diagnoses may appear surprising, given that cardiorespiratory diseases are among the most common underlying causes of breathlessness. However, many pathways apply strict pre-referral screening in primary care, filtering out easier to identify conditions like COPD or asthma before referral and leaving the unexplained or the more complex cases to be referred. The pathway can therefore reduce respiratory clinic waiting lists while directing patients who require specialist care more quickly to respiratory services.

Early intervention may be particularly important for people of working age, who one respiratory consultant estimated made up 30–40% of referrals. Identifying and addressing the underlying cause can help people remain in or return to work while preventing the physical and psychological consequences of

prolonged inactivity.²¹ This creates benefits beyond the NHS by supporting economic participation and reducing the wider costs of untreated breathlessness.

For patients, timely diagnosis represents a critical window of opportunity for clinicians to intervene. Delays leave patients frustrated by a lack of explanation, often leading them to avoid everyday activities for fear of exacerbating their symptoms. This can contribute to weight gain, musculoskeletal problems, physical deconditioning and psychological morbidity, further increasing the complexity of their management.

“

Patients can experience a self-perpetuating cycle of physical and psychological decline.”

– Respiratory consultant

Earlier diagnosis and appropriate management could therefore help prevent deterioration and comorbidities, particularly among older adults, while reducing pressure on the NHS.

Better data is needed to demonstrate long-term impact

However, the available data does not yet allow the long-term impact of the pathway on patients and the NHS to be quantified. The pathway's primary diagnostic role means pathway leads often have limited visibility of what happens to patients after diagnosis. Fragmented links between CDCs, primary and secondary care make it difficult to know whether patients receive appropriate management or how the pathway affects long-term outcomes. This is exacerbated by the lack of available data, which limits the ability to demonstrate whether faster diagnosis translates into better care, improved outcomes and more efficient use of NHS resources.

Maximising the pathway's value therefore requires diagnosis to be better integrated into the wider patient journey. Patients should be able to transition seamlessly from diagnosis to appropriate management, while consistent data collection should enable outcomes, onward referrals, treatment and subsequent use of healthcare services to be tracked. This would strengthen continuity of care, support more efficient use of NHS resources and provide the evidence needed to demonstrate the pathway's full impact.

What worked well: factors for successful implementation

Across conversations with pathway leads, consultants, clinical leads and commissioners involved in the pathway implementation, four common factors underpinned successful pathway implementation and delivery:

1. Senior leadership backing
2. Early and sustained stakeholder engagement
3. Clinical trust and buy-in
4. Robust digital infrastructure

However, these successes remain localised, with the conditions that enable successful implementation not yet consistently replicated across the country.

Stakeholders consistently identified senior leadership support as critical to establishing and maintaining the pathway. Pathway leads at successful sites cited the support of ICB clinical leads and Trust senior leaders, whether in advocating for the pathway to executive teams for commissioning, allocating time to train GPs on referral criteria and pre-referral requirements, or promoting the pathway with local GP federations and primary care networks. CDCs in East and South East England highlighted their ICBs' respiratory networks and respiratory leads as the critical lynchpins in getting the pathway established with one ICB described as "knocking on the doors" on how they could support them. The clinical leads provided support in developing commissioning documents and business cases, promoted the pathway with local primary care networks and shared pathway data with ICB executive teams to secure backing.

Beyond leadership support, successful implementation depended on early engagement with stakeholders, establishing what resources were needed, how the pathway would fit into their existing workplans and building the trust required for them to use it. All pathway leads emphasised the importance of involving key groups from the onset such as the CDC manager to develop referral forms and secure access to tests and clinic rooms; cardiology and respiratory consultants to co-develop and sign off the pathway; and primary care professionals to collaboratively build a pathway they would actually use. Some pathway leads maintained these relationships through regular stakeholder meetings.



Securing early engagement and support from cardiology and respiratory consultants was essential to building clinicians' trust in the pathway, given the pathway is often run by healthcare scientists. One healthcare scientist described securing support by framing the pathway's value to their clinical team as "mutually beneficial as it frees up time for consultants and upskills a workforce". Healthcare scientists delivering the pathway outside the CDC model similarly reinforced the importance of early buy-in, co-developing the pathway with key groups to ensure it was usable rather than "shoving it down their throats afterwards".

A further element of successful implementation was strong digital infrastructure. All stakeholders highlighted the importance of interoperable IT systems and robust data collection in enabling a streamlined service with real-time evaluation and analysis. The most efficient pathways had the CDC's digital systems automatically linked to primary care records, enabling streamlined referrals and allowing patient history and journey to be tracked within a single system. One CDC in East England achieved this by working directly with their Trust's digital team to link their digital clinical record system to the GP's electronic patient record system, resolving a major barrier of clinicians trying to collate information from separate, disconnected platforms. Seamless information sharing therefore improves patient experience while providing clinicians with the full medical history making diagnosis easier and quicker.

Beyond the operational benefit, data collection played a critical role in demonstrating the pathway's benefits to patients and its cost effectiveness for the Trusts. One healthcare scientist leading the pathway in North West England described data as "the bread and butter" of the service, explaining that it "gave us ammunition" to convince executive teams to continue commissioning the pathway. A newly established pathway team highlighted the importance of identifying from the outset the data needed to demonstrate its impact, including referral-to-treatment times, waiting times and follow-up appointments, and using these measures to compare performance with the general respiratory clinic.

“

The cost-saving argument at the end carried the most weight.”

– Respiratory consultant

Challenges and barriers to implementation

While factors such as early engagement, senior leadership support and strong digital infrastructure enabled success at individual CDCs, these conditions were not consistently in place across the country. As a result, progress often depended on the energy, relationships and dedication of specific individuals.

Conversations with stakeholders identified seven barriers to implementation:

1. Leadership and prioritisation
2. Accessibility and logistics
3. Workforce capacity
4. Funding uncertainty
5. Pathway design and the lack of national guidance
6. Primary care engagement
7. Digital infrastructure and data standards

Together, these findings highlight the conditions needed to move from successful local implementation to sustainable national rollout.



Leadership and prioritisation

A significant barrier to establishing the pathway was the lack of prioritisation of respiratory care at system level. Multiple commissioners and clinicians reported that executive teams at ICBs were reluctant to sign-off or approve the pathway because it was not seen as a priority. Reflecting this low prioritisation, one consultant said their Trust viewed the pathway as “a luxury”. One commissioner had difficulty engaging, let alone convincing, executive teams given its low priority in the ICB, which required justifying a move of limited resources away from prioritised ICB workstreams such as cancer care and cardiovascular disease management to meet nationally set targets. This revealed a contradiction in the roll out with the pathway named as a priority in various NHS planning documents yet unable to compete locally for the resources needed to deliver it. Where the pathway did succeed in getting approved, this often depended on a “motivated and enthusiastic group of people to get it going” instead of system-level support.

“

The pathway is frail, but we get through with passion and energy.”

– Pathway lead

Beyond the challenge of low prioritisation, a related barrier was the absence of the structural leadership needed to champion the pathway and hold the system to account. The restructuring of ICBs and the subsequent loss of clinical leadership roles compounded this problem. All stakeholders raised concerns about who would support and advocate for the pathway within the ICB system going forward. Without a respiratory lead at the ICB, or a respiratory network pushing for better respiratory care, pathway leads found it difficult to maintain executive team’s support for the pathway, undermining its sustainability. This contrast was particularly evident at a CDC in the South West, where a strong relationship with the executive team was established through its respiratory clinical lead, but was lost when the clinical lead position was scrapped. This shows that the pathway’s viability remains too dependent on personal relationships and individual efforts rather than embedded within system-level leadership structures. Another pathway team cited loss of Trust-level support as the key reason it stopped delivering the pathway. Without support from respiratory clinical leads, pathway development in some CDCs became what one healthcare scientist described as a “bottom-up approach”, relying on a “just graft and do it yourself” attitude among frontline staff.

Accessibility and logistics

One challenge concerned the practicalities of delivering the pathway from a CDC, whether based in a hospital or at a bespoke site. CDCs set up within hospital buildings faced barriers accessing clinical rooms and appropriate tests to review and diagnose patients within the promised single appointment. The growth in bespoke CDC sites was intended to address this problem providing dedicated space and testing outside the acute hospital setting and for the most part this worked, with most bespoke CDC sites operating without this constraint. However, the problem has not disappeared entirely. CDCs in the South East and North West of England reported not having enough clinical rooms to see patients as the CDCs expanded to include additional pathways, stretching the existing capacity.

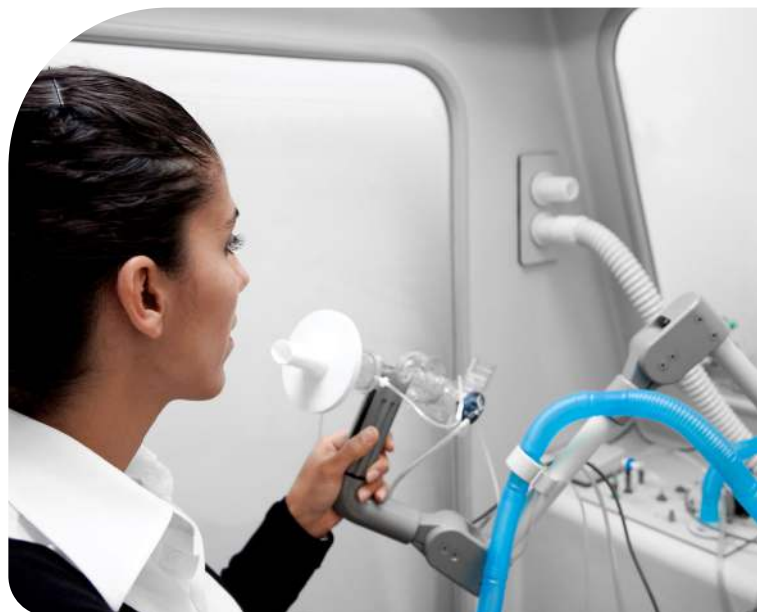
A more significant challenge was geographical accessibility. Although CDCs were established to bring diagnostics closer to communities, some stakeholders found their local CDC less accessible than existing hospitals, particularly in rural and deprived areas. One CDC in East England found that patients travelled 20 to 30 miles on average to access tests, while a CDC in the West Midlands reported that local hospitals were closer to patients than the CDC itself, with around 10% of patients unable to access the CDC at all. Limited public transport

and the socioeconomic circumstances of many people experiencing chronic breathlessness meant that free parking alone was insufficient to overcome these barriers.

One ICB rejected a CDC-led pathway entirely due to concerns around accessibility and the ability to provide care closer to patients. As CDCs are designed to serve a large catchment population, the ICB was concerned that people without good transport links would be unable to access the service. Another Trust covering a large rural area, implementing a Trust-wide pathway rather than a CDC pathway, highlighted the inaccessibility of its local CDC, which would force patients to travel long distances and risked exacerbating health inequalities in areas without a CDC. In both cases, they preferred delivering care through a neighbourhood model, establishing a breathlessness pathway in neighbourhood hubs based in health centres or GP surgeries, which patients could access more easily. As national policy shifts towards a neighbourhood model of care, these cases highlight the need for a flexible delivery model that reflects local population needs, particularly in rural areas, areas with limited public transport and those without an existing CDC, rather than relying solely on a CDC-based delivery model.

Workforce capacity

Workforce shortages and high staff turnover were significant barriers to pathway implementation, which requires access to staff qualified to carry out diagnostic tests including X-rays and echocardiograms. At some CDCs, this resulted in a “round robin” effect, with essential staff moving between local CDCs and limiting each CDC’s capacity to see patients. One CDC in South West England used hospital staff to cover appointments, which was unsustainable and had a knock-on effect on patient care at the hospital itself. These experiences are consistent with a wider national picture with recent data from Taskforce member the Royal College of Radiologists showing that 88% of CDCs still rely on existing NHS staff²² rather than dedicated CDC staff. Limited staffing presented a significant barrier making it difficult to set up the pathway initially, meet growing demand, and expand the service. Even where CDCs were able to recruit enough staff to run the pathway day to day, there was often no capacity to cover holiday or sick leave, placing immense pressure on the workforce.



In response, some Trusts trained existing staff to build the clinical skills needed to fill workforce gaps, though this depended on securing extra funding and on Trusts being willing to provide protected learning time. Workforce shortages were also a key reason one Trust decided against a CDC-led pathway altogether, opting instead to reorganise existing primary care staff who understand the local needs and resources to deliver a breathlessness pathway themselves. Another Trust, delivering a breathlessness pathway outside the CDC model on a Trust-wide basis, had greater flexibility than fixed-site CDCs, allowing it to move staff and funding between teams to “even out the teams and capabilities.” This allowed resources to be distributed more flexibly, enabling patients to receive care as close to home as possible, with local hospitals used for tests rather than requiring patients to make longer journeys to a CDC.

Funding uncertainty

While the pathway has been successful in providing early and fast diagnosis, its ability to continue and expand has been undermined by the funding model.

One respiratory consultant captured what the funding uncertainty felt like day to day, describing it as “trying to maintain enthusiasm and drive without any knowledge of funding”. Multiple pathway leads felt the initial funding period was too short, underestimating the time needed to develop, set up and run the pathway. The short timeframe also created immense pressure for the pathway teams to prove their value to the Trust. Several pathway leads noted it took over six months to recruit critical staff such as patient navigators, administrators and radiologists, a delay made worse by the fact that original funding often did not cover staffing costs at all, forcing pathway leads to seek further funding from Trusts under significant budget constraints and NHS-wide workforce shortages. This created a cycle in which services were expected to demonstrate impact before they had sufficient time or capacity to establish the pathway, generate activity and collect the data needed to show value.

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One year funding is not enough... more time is needed to develop a business case.”

– Respiratory consultant

This frustration and concern over funding uncertainty was captured by one CDC in East England. Despite being seen as an “exemplar” service recognised by various organisations and meeting every requirement set out in national plans, its lead respiratory consultant described securing yearly funding as an “ongoing battle,” noting that “the reality on the ground is that you are low priority for funding.”

Pathway design and the lack of national guidance

Setting up the pathway within the initial funding period was made more difficult by the lack of guidance on how best to design and deliver it. This meant many pathway leads were independently solving problems that other pathways had already worked through, spending scarce funded time troubleshooting and refining processes rather than delivering care.

Duplication of efforts were evident in the design of the pathway. Various pathway leads described the difficulty of developing a referral form that captured the correct clinical investigations from both cardiology and respiratory while remaining easy for primary care to use. Other barriers included the administrative burden of writing governance documents such as standard operating procedures, which consumed a large amount of the initial funding period, time that could have gone towards seeing patients.

Some pathway leads minimised this administrative burden by initially piloting the pathway on a small scale within a hospital, using the experience to test and refine the pathway and support their case for CDC funding. However, this required explicit support and buy-in from Trusts and clinicians before funding was approved. Others worked closely with a small number of GP surgeries to 'troubleshoot' the pathway and refine the process before expanding to more

practices. While these approaches helped services test and refine the pathway, they simultaneously made it harder to generate sufficient activity and data to demonstrate value. One newly formed pathway team started replicating documents, including referral forms and letters, from other successful teams to save time.

A common request among stakeholders was for a standardised national approach to improve efficiency, particularly given the time pressure of setting up a new service. Standardised documents and templates would mean new services do not have to "reinvent the wheel every time" or start from a blank page and would allow lessons from successful sites to be applied elsewhere. This would also formalise some of the practices pathway teams were already doing independently to improve the pathway design. Beyond shortening approval times, standardisation would support agreement on workforce requirements, ensure appropriate referrals and save valuable time in establishing and running the pathway. Standardised templates would therefore enhance operational efficiency while allowing enough flexibility for teams to adapt to local circumstances, for example, the range of diagnostic tests already accessible to primary care, or the specific population profile they serve.

Primary care engagement

The pathway relies heavily on primary care referrals to operate, making primary care awareness and support essential to its success. A recurring barrier, however, was low awareness and engagement among primary care professionals, leading to low referral numbers.

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Referral into the service lives or dies by the number of promotions.”

– Pathway lead

Many pathway leads, having secured funding, found themselves having to promote the pathway to primary care while simultaneously developing forms, recruiting staff, and seeing patients. Since CDCs are activity-based services with specific targets tied to funding, engagement was essential to securing enough patients to meet those targets, yet the time spent on self-promotion reduced the time available for service delivery, creating tension between short-term funding pressures and long-term sustainability.

To secure referrals, pathway leads employed a range of tactics, including visiting GP surgeries, presenting at protected learning time sessions, targeted mailing, and evening events. One lead

noted that by the time this promotional work had generated meaningful referrals, only four months of initial funding remained. Despite these efforts, many pathway teams still experienced low referral numbers, with some seeing an average of only 100 patients a year despite being based in areas of high deprivation. A healthcare scientist lead at a CDC in South East England described the experience as “almost like talking to a brick door... hoping some form of messages get somewhere in the system to somebody”. A recurring impression from meetings with GP surgeries was that “GPs didn’t know what [a] CDC was and what it was for”, reflecting a general unfamiliarity with CDCs, on top of which primary care also had to be introduced to a new and unfamiliar pathway operating within them. Even where referrals initially increased following direct engagement, they tended to decline again over time, suggesting it required consistent, intensive promotion rather than one-off outreach. Pathway leads who sought ICB support for promotion often found this difficult too, with one noting it was “really hard to find who my ICB comms team are” and that even once contact was made, promotion was limited to a mention in a monthly newsletter, easily lost among other information.

Some pathway leads managed to secure more consistent referrals by relying on a small number of GP surgeries or building a close relationship with one specific practice. While this helped generate referrals, it limited the potential to expand the service and demonstrate its value

and could contribute to geographical disparities in access. A more promising approach came from non-CDC pathways, which broadened the range of primary care professionals able to refer, including nurses and paramedics, and adapted their referral form accordingly, alongside expanding promotion beyond GPs. This led to increased referrals which suggests that widening the referral eligibility could help sustain referral numbers more than GP focused promotion alone.



Digital infrastructure and data standards

Digital infrastructure presented additional barriers to successful implementation, with fragmented systems between CDCs and primary care and inconsistent data standards limiting information sharing, continuity of care and the ability to demonstrate value for funding decisions.

Disjointed IT systems presented a significant challenge to both referrals and clinical assessment. Primary care generally has a streamlined referral procedure for hospital or specialist care using an electronic patient record system with automatically completed referral forms.²³ The referral system to CDCs, by contrast, is often complex and disjointed, adding to the workload of an already overstretched primary care workforce and discouraging engagement with an unfamiliar pathway. This disjointed system meant GP practices were often reluctant

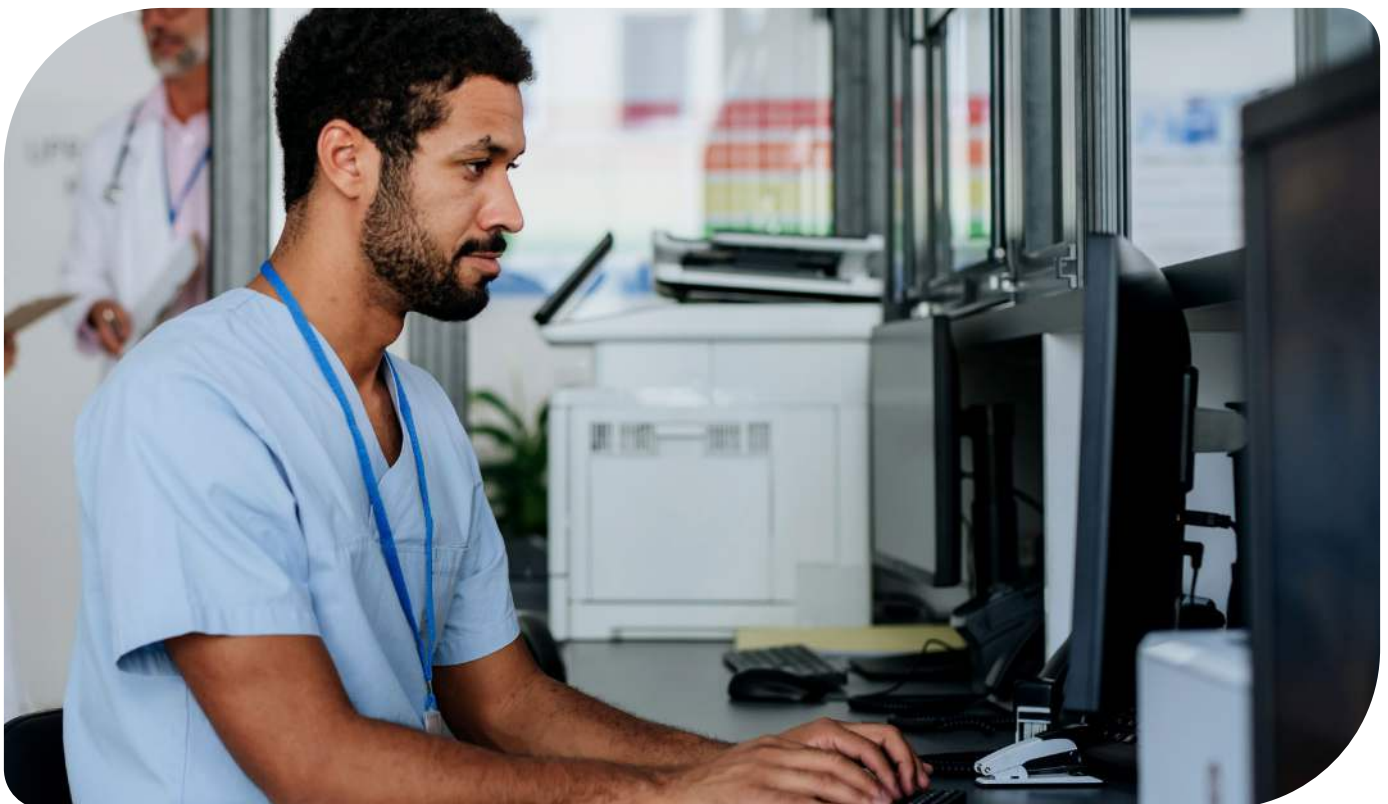
to use a separate digital system to refer, and it made it difficult for CDCs to access full patient medical histories when carrying out investigations or demonstrating the pathway's value. In some cases, this led to practices using the wrong referral form altogether, for example referring patients to a spirometry pathway or the general respiratory clinic instead. These referrals had to be returned to the GP for re-referral, delaying diagnosis and creating additional administrative work.

This fragmentation also limited clinicians' ability to see a patient's full medical history, including their previous appointments, referrals, emergency visits, follow-ups and treatments, undermining the ability to carry out a full clinical assessment. This was compounded by the fact that CDCs are typically connected to only one Trust's digital system. Where a

CDC served patients from multiple Trusts or even multiple hospitals, this problem became more severe, since the CDC could typically only access patient data from the one Trust it was connected to, meaning information held by other Trusts was often inaccessible to the CDC. Even when data could be accessed, disjointed clinical records systems meant data was often missing or lost, a problem amplified by inconsistent coding between primary and secondary care.

One pathway lead overcame this by working closely with its Trust's digital team to link the CDC's clinical record system directly to the GP's digital system, streamlining referrals and enabling seamless sharing of medical history. Other CDCs lacking this infrastructure resorted to using spreadsheets to track patients, undermining the pathway's overall effectiveness.

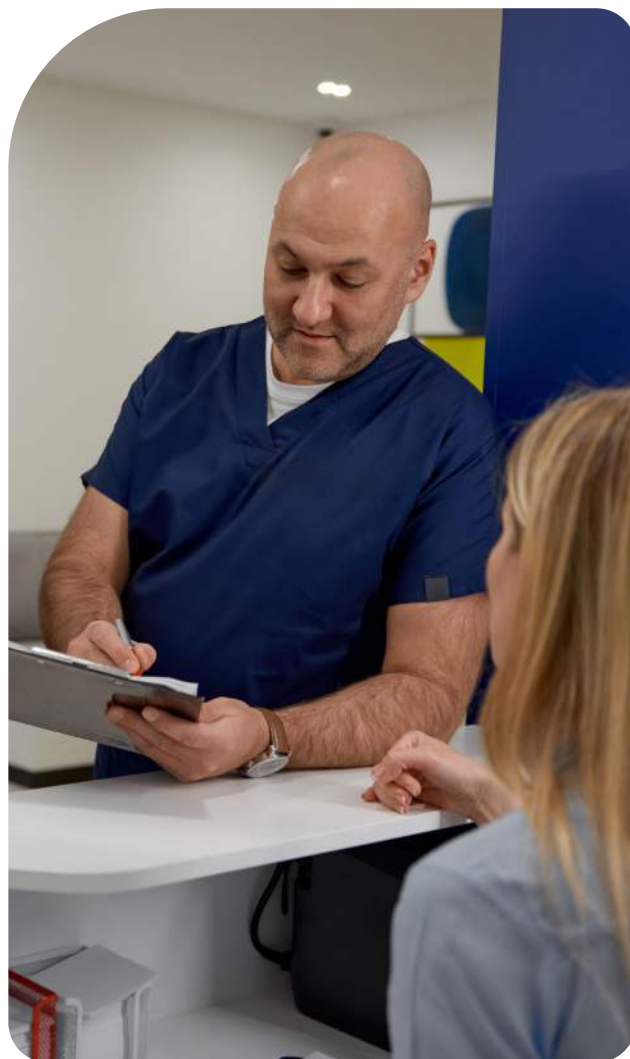
Beyond interoperability, weak data standards also made it harder to write the robust business cases required to secure funding, compounding the funding pressure. As one commissioner put it "health economics was key" to securing funding yet without clear agreement on what data should be collected and how it should be analysed, pathway teams struggled to gather the right evidence. This was exacerbated by the limited digital infrastructure causing fragmented databases. Some pathway leads proposed a national database drawing on data from all CDCs, enabling population-level analysis of the pathway's benefits that individual CDCs could then use to extrapolate localised impact and strengthen their own funding cases. A newly established CDC pathway illustrated the benefit of shared data by using another CDC's data to convince its Trust to commission the pathway in the first place.



Recommendations

The Adult Breathlessness Pathway can deliver significant benefits for patients and the health service when it is implemented effectively, including faster diagnosis, better patient outcomes and lower healthcare use. However, its success has too often depended on individual CDCs, local champions and personal relationships.

This has created variation in implementation and left services to overcome systemic barriers themselves, including funding uncertainty, limited national guidance, fragmented digital systems, leadership challenges and low awareness among primary care. The following recommendations aim to address these barriers and create the conditions needed for sustainable implementation and rollout across the country.



Recommendation 1:

Establish respiratory care as a national priority

Respiratory care, and breathlessness in particular, remain a low priority for ICBs and Trusts despite being included in key national planning documents. A clear national mandate would give ICBs and Trusts the authority and expectation to prioritise respiratory care including the breathlessness pathway, reducing variation in implementation.

We recommend that the Department of Health and Social Care:

- Establish respiratory care as a national priority through a Modern Service Framework, with clear expectations for ICBs and Trusts to support implementation of pathways like the Adult Breathlessness Pathway.

Recommendation 2:

Mandate and protect clinical leadership at ICB level

Successful implementation has too often depended on motivated individuals supported by clinical leadership. This creates vulnerability when individuals move roles or leave. Named clinical respiratory leads within every ICB would provide sustained accountability and a direct route to executive teams.

We recommend that NHS England, its successor bodies and Integrated Care Boards:

- Mandate and protect named clinical leadership roles within every ICB, with responsibility for supporting respiratory pathway implementation and providing a direct link to executive leadership to hold the system to account.

Recommendation 3:

Establish a national implementation and evaluation toolkit

Many pathway leads have had to build the pathway from scratch, developing referral forms, governance processes, evaluation measures and promotional materials independently. This duplicates efforts, delays implementation and creates variation between services.

We recommend that NHS England and its successor bodies:

- Develop a national implementation and evaluation toolkit containing standardised pathway guidance, referral and governance templates, workforce and training guidance, evaluation measures and communication materials.
- Publish a national dataset and dashboard to monitor pathway activity, outcomes and impact, and provide the evidence needed to develop robust business cases for sustained funding.

Recommendation 4:

Deliver joined up digital infrastructure and national data standards

Fragmented IT systems and inconsistent data practices have resulted in missing information, inappropriate referrals and unreliable data, limiting both continuity of care and the ability to demonstrate pathway impact. Consistent data standards along with joined up digital infrastructure would streamline patient care and enable more effective information sharing across services.

We recommend that the Department of Health and Social Care:

- Implement the single patient record within the established timeframe following Royal Assent of the NHS Modernisation Bill, ensuring medical history can be shared and accessed easily to ensure optimal care for patients through better continuity of care.
- Join up IT systems between CDCs and primary and secondary care, to streamline referrals and ensure correct coding for reliable data collection and analysis.

Recommendation 5:

Commit to a multi-year funding model

The short-term funding model does not reflect the time required to recruit staff, develop the pathway, establish referral routes and generate sufficient evidence of impact. In some cases, recruitment of critical staff alone has taken more than six months, placing additional pressure on existing workforce and reducing the time available to demonstrate the pathway's impact before funding decisions are required.

We recommend that NHS England and its successor bodies:

- Commit to a multi-year funding model that gives pathway leads sufficient time to recruit staff, establish and evaluate the pathway, demonstrate its impact and develop a sustainable business case for long-term delivery.

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The secretariat for the Taskforce for Lung Health is provided by Asthma + Lung UK.



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