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WHITE PAPER

# Breathlessness and symptom-based diagnostic pathway transformation

*Why Digital Diagnostic Pathway Tools can enable more effective diagnostic approaches*

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# Introduction

Breathlessness is a common symptom affecting around 10% of the UK population with higher prevalence in older age groups[1]. The diagnosis of the underlying causes is challenging due to multiple contributing factors, overlap between symptoms and the potential diagnosis of a combination of conditions. These factors along with the disjointed nature of diagnosis pathways across care settings in the UK is having a profound impact on wider demand for health services. The delayed diagnosis of patients is driving more unscheduled care events, such as emergency hospital admissions, and results in poorer health outcomes.

Digital Diagnostic Pathway Tools offer a solution to improve the patients' journey to diagnosis by joining up data across settings. However, by working in tandem with innovative point of care tests, and coordinated specialist tests in CDCs, they can transform how breathlessness diagnostic pathways work, dramatically reducing the time to a complete diagnostic outcome. They also offer the opportunity to improve care, establishing integrated care registries at point of diagnosis for population health management of the underlying conditions, enabling risk stratification and personalised management to improve outcomes following diagnosis.

# Challenges in effective breathlessness diagnosis and the impact of delays

The causes of breathlessness commonly include a range of cardiorespiratory diseases such as heart failure, chronic obstructive pulmonary disease (COPD) and asthma, with commonly associated comorbidities such as anxiety, depression, low physical activity and deconditioning.

Diagnosis of the underlying cardiorespiratory causes of breathlessness has been historically difficult and resources have not recovered following the pandemic. In cardiovascular diseases, waiting lists rose to 419,039 at the end of April 2024 in England, nearly double the pre-pandemic figure[2], with 80% of heart failure diagnoses being made in hospital following an admission[3].

Research from leading lung charity Asthma + Lung UK reveals that nearly 1 in 4 people surveyed with COPD waited more than five years to be diagnosed. In addition, 23% of

[1] https://www.asthmaandlung.org.uk/symptoms-tests-treatments/symptoms/breathlessness/what-breathlessness
[2] https://www.bhf.org.uk/what-we-do/news-from-the-bhf/news-archive/2024/june/heart-care-waiting-list-grows-again
[3] https://heart.bmj.com/content/104/7/600

people surveyed said they were misdiagnosed as their doctor thought they had a chest infection or cough. Other key problems included access to care with 1 in 4 saying they couldn't get an appointment and 1 in 5 being unable to access diagnostic tests[4]. One GP commented that for breathless patients "access to testing is often physically challenging, time consuming and potentially prohibitively costly for many patients leading to delays in results or even missed tests and therefore an incomplete picture".

The impact of delayed diagnosis and suboptimal care is significant. Breathlessness accounts for approximately 5% of emergency department presentations, 4% of GP consultations, and is reported by patients in 12% of all medical admissions[5]. In addition, the delayed diagnosis of underlying conditions such as heart failure and COPD have an adverse effect on health outcomes. 52% of patients with heart failure do not survive more than 5 years after diagnosis[6]. COPD accounts for 1 in 8 of all hospital admissions and delayed diagnosis increases the likelihood of flare-ups in the condition, called exacerbations[7], which in themselves results in poorer outcomes for these patients[8]. These delays have a significant impact on both specialist services and the general demand for healthcare resources in the UK.

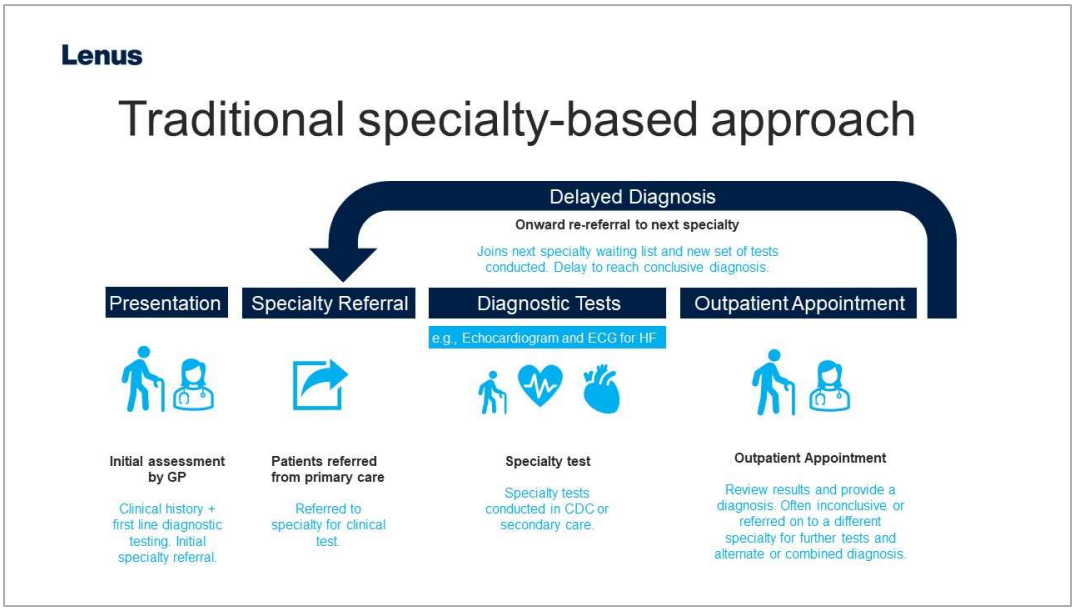


Figure 1. Traditional specialty-based referral pathway

[4] https://www.asthmaandlung.org.uk/media/press-releases/quarter-people-copd-waiting-5-years-diagnosis
[5] https://www.england.nhs.uk/long-read/adult-breathlessness-pathway-pre-diagnosis-diagnostic-pathway-support-tool/
[6] https://www.bhf.org.uk/for-professionals/healthcare-professionals/blog/2019/rushed-to-hospital-when-heart-failure-isnt-diagnosed-early-enough
[7] https://erj.ersjournals.com/content/54/suppl_63/PA2497 /
[8] https://thorax.bmj.com/content/67/11/957

# NHS initiatives to address breathlessness diagnosis

Following the pandemic, NHS England has invested in a range of programmes to help address wider elective waiting times and specifically diagnostic pathways.

New guidance on **symptom-based diagnosis in breathlessness pathways**, released by NHS England in 2023[9], provides a blueprint for systems to address the diagnosis of the underlying causes of breathlessness. The guidance aims to address chronic breathlessness and the support tool emphasising early, accurate diagnosis by aligning clinical practice with published guidelines. It advocates for objective assessments, holistic approaches, self-management advice, and mental health support, highlighting that delays and misdiagnoses are common, and timely intervention is crucial.

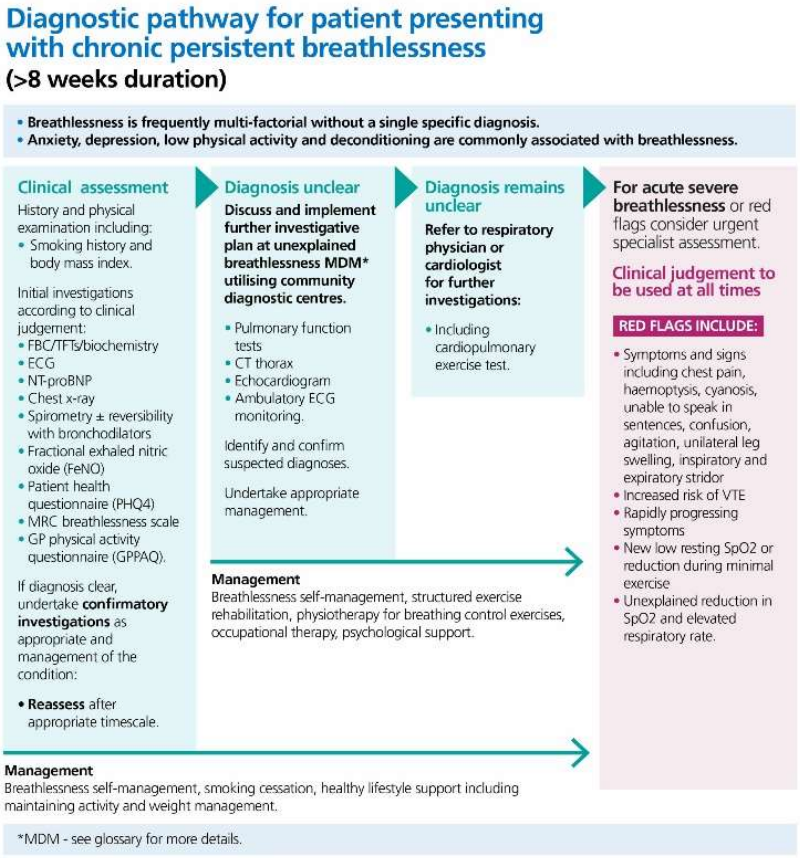


Figure 2. NHS England Diagnostic pathway for patients presenting with chronic persistent breathlessness[10]

[9] https://www.england.nhs.uk/long-read/adult-breathlessness-pathway-pre-diagnosis-diagnostic-pathway-support-tool/
[10] https://www.england.nhs.uk/wp-content/uploads/2023/04/diagnostic-pathway-diagram-scaled.jpg

The **Community Diagnostic Centre (CDC)** programme is a significant initiative by NHS England to address elective care recovery following the pandemic and address gaps in testing capacity and accessibility. The programme is part of a broad strategy to modernise and improve diagnostic capabilities, reduce waiting times and ultimately improve population health outcomes by diagnosing health conditions earlier, faster and more accurately. Establishing these new centres in community locations was designed to make diagnostic services more accessible and alleviate pressures at acute hospital sites. Over 7 million tests, checks, and scans have been delivered since the programme's inception in July 2021 with 160 sites now operational.

The **GP Direct Access** initiative allows general practitioners (GPs) to directly order diagnostic tests for patients with concerning symptoms, even if they fall outside the National Institute for Health and Care Excellence (NICE) guideline threshold for an urgent referral. Through this initiative, diagnostic scans such as CT scans, ultrasounds, or brain MRIs can be arranged for patients in either CDCs or secondary care centres. The scheme aims to cut down wait times to as little as four weeks for key tests.

Both initiatives will increasingly provide access to tests for breathless patients to help to inform a diagnosis, however waiting times remain stubbornly high due to historical referring practices and the complexity of capturing and sharing the appropriate data between settings and specialists to reach a formal diagnosis.

Finally, breathlessness symptoms and delayed diagnosis also have a high prevalence in areas of deprivation. Access to care in these communities through socioeconomic barriers is also a key consideration in how to treat the underlying causes. People from poorer communities are more likely to have cardiorespiratory conditions and less likely to access care services[11]. The NHS England **Core20PLUS5** initiative has focussed on equitable access to care to address these disparities, and this funding also covers key cardiorespiratory conditions associated with breathlessness symptoms.

## Digital pathway tools – digitising the patient journey

The development of Digital Diagnostic Pathway Tools has made significant impacts in automating clinical workflows for single condition diagnostic pathways such as Heart Failure and COPD.

These new digital pathways address the challenge raised by the All-Party Parliamentary Group for Diagnostics in a report published in January 2024 that highlighted the lack of digital tools to help streamline pathways, improve efficiency and

[10] https://www.cqc.org.uk/publication/state-care-202122/inequalities

address data interoperability and care coordination challenges between primary and secondary care[12].

By plugging in on top of existing systems to aggregate referral data, supporting collection of physiology, Patient Reported Outcomes (PROs), patient history and test results, Digital Diagnostic Pathway Tools allow rapid diagnosis in community settings often without the need for a specialist outpatient diagnostic appointment.

Solutions allow clinical and administrative teams to track and monitor patient journeys through the vetting, appointment and outcome stages, addressing missing data or missed appointments, and allow a diagnostic outcome to be reached virtually.

In addition, digital tools can be agnostic to where the tests and supporting information is captured. This enables data from primary, community and secondary care settings to be shared to reduce duplication and enable standards-based referral and triage with collaboration across specialisms to reduce the time to diagnosis.

These tools can also provide detailed reporting capabilities for DM01 (Diagnostics waiting times and activity)[13] operational and re-imbursement reporting, and national registries of diagnosed patients.

## Evidenced benefits

Lenus Diagnose, as an example tool, has generated significant evidence of benefits for heart failure diagnosis pathways. It was developed and implemented in the Optimising a Digital Diagnostic Pathway for Heart Failure in the Community (OPERA) Study in Glasgow, Scotland. The study coordinated standards-based referral and triage, co-located community-based echocardiograms and related tests. This, along with Advanced Nurse Practitioners, enabled some patients to receive outcomes and immediately start treatment plans, quickly reducing backlogs. The initial diagnosis was subsequently reviewed by a cardiologist digitally with ongoing treatment plans generated. The transformed pathway significantly reduced the number of patients requiring an additional diagnostic outpatient appointment.

A Health Technology Assessment (HTA) evidenced a 78% reduction in time to diagnosis and a 72% reduction in time to treatment for Heart Failure patients. It reduced patient visits by over 50%, significantly improving the patient experience and reducing admissions while patients were on the waiting list for diagnosis. As a result,

[11] https://www.rcpath.org/static/c131184d-fc49-4b75-837303c677817071/APPG-for-DiagnosticsCDC-Report-Jan-2024.pdf
[13] https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/diagnostics-waiting-times-and-activity-dm01

the Lenus Diagnose tool was found to be highly cost-effective, with an incremental cost-effectiveness ratio of £4,700 per QALY gained at a £20,000 willingness-to-pay threshold[14].

Following these results in a cardiovascular diagnosis pathway, Lenus Diagnose has subsequently been applied to direct access spirometry for COPD and associated respiratory conditions, enabling over 2,500 patient diagnostic outcomes in the first 6 months of operation.

However, when applying the tools to more complex symptom-based pathways such as breathlessness, the benefits of opening-up traditional testing pathways across specialties are even greater, enabling coordinated parallel testing in CDCs.

## Redesigning breathlessness pathways

Beyond digitising existing pathways and processes, the use of Digital Diagnostic Pathway Tools offers the potential to transform care pathways to provide even greater benefits, especially in complex and uncertain diagnosis scenarios such as Breathlessness.

Many standard diagnostic approaches remain, which rely on sequential specialty referrals, rather than using rapid testing and CDC resources to rule-out potential breathlessness causes in a coordinated and optimised pathway. By using Digital Diagnostic Pathway Tools, there is no longer the need for prolonged singular and sequential pathway referrals, allowing a more coordinated, cross-specialty approach with digital MDTs and data-driven diagnosis to streamline breathlessness pathways.

## Integrating and accelerating Point-of-Care testing

As the availability of cheap and effective point of care testing against a range of disease indicators gains pace, more early testing can ensure that onward referral to additional tests and specialists are more precisely determined.

As described in the A+LUK report[15], delayed diagnosis is not only the result of slow access to the right tests. It is also accessing the correct tests in the first place. Due to the complex nature of breathlessness, patients are often referred into one diagnostic

[14] https://lenushealth.com/evidence-1/lenus-diagnose-evidence/opera/
[15] https://www.asthmaandlung.org.uk/sites/default/files/2023-03/delayed-diagnosis-unequal-care.pdf

pathway such as “breathlessness - suspected respiratory disease”, only to reach the end of that journey for the diagnosis to be inconclusive with another suspected diagnosis or comorbidity requiring further testing.

With every minute of care provision counted and pressured, GPs and other health professionals often refer based on experience rather than taking the additional time proposed in breathlessness guidelines to access new and review previous tests before onward referral.

While choice and the application of clinical experience is very welcomed, the volume of patients who are sent down one pathway only to reach the end and find out it is not what was suspected is significant. Given that this process usually takes weeks if not months and can end without conclusive diagnosis, it is not only worrying but often life-threatening.

With the onset of new innovations in testing such as NTPro-BNP for heart failure and Feno testing for asthma and other respiratory conditions, there is now a case to be made that all breathlessness patients should receive these relatively cheap and easily deployed tests at point of presentation in primary care or at home, and subsequent diagnostic journeys should be coordinated across specialisms, rather than individual departments and tests.

While Spirometry testing for respiratory conditions remains challenging, with difficulty generating successful results and a fragmented commissioning environment, new technologies can assist the confidence in the results generated, while potential replacement diagnostic devices are in development. These new point of care testing solutions all generate digital outputs that can be consumed by pathway tools and shared across settings.

## Coordinated CDC testing

With the arrival of CDCs, which include both cardiovascular testing (such as echocardiograms and ECGs) and respiratory tests (such as lung function and spirometry) along with CT and MRI, there is an argument that testing referrals can be coordinated across conditions in a one-stop shop capability.  By combining tests in one visit, a diagnosis can be reached more rapidly while also reducing the impact of multiple visits on the patient.

With Digital Diagnostic Pathway Tools, patients’ diagnostic outcomes can be discussed in MDTs that include a range of specialists and the referring GP, if required, to confirm the diagnosis.

New breathlessness pathway approaches can be rapidly and effectively implemented with digital tools, saving cost and time and most importantly reducing time to diagnosis to improve patient outcomes and reduce unscheduled care.

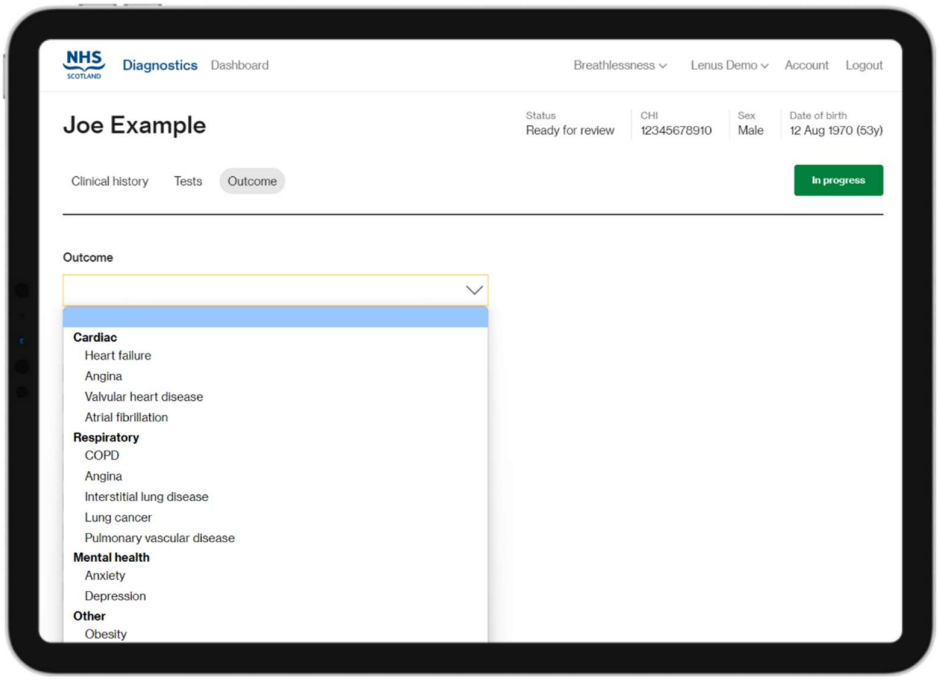


Figure 3. Possible diagnostic outcomes

## Enhanced post-diagnosis care and population management

With investment in CDCs, direct GP access, new guidelines for breathlessness diagnosis, and the offer of digital diagnostic tools, the way is set to accelerate time to diagnosis and treatment for these patients. Using Digital Diagnostic Pathway Tools to support diagnosis can also enable better care following diagnosis utilising the data collected along the way.

While national registries assist in understanding disease prevalence and wider research, they have limited impact on patient management. Diagnostic data is often collected to support a diagnosis but then filed in a letter and attached to the patient record with limited onward benefit.

By digitally capturing this data in a structured machine-readable format, new insights and improved patient care can be delivered, including patient and population-based risk stratification insights. Operational registries of patients can enable appropriate

management plans to be delivered for these patients and enable systems to track, intervene and manage disease prevalence more effectively across a range of system settings.

With structured data insights at point of diagnosis, patients at immediate risk of admission or adverse events can be highlighted and more tailored care plans can be implemented. This provides for more personalised care allowing high or rising risk patients to access additional treatments such as pulmonary rehabilitation, ventilation services and early access to new biologics.

This digital diagnostic approach provides the foundation to support a more proactive model of management for long-term conditions where resources can be focussed on those most at risk rather than in reaction to demand and decompensated disease.

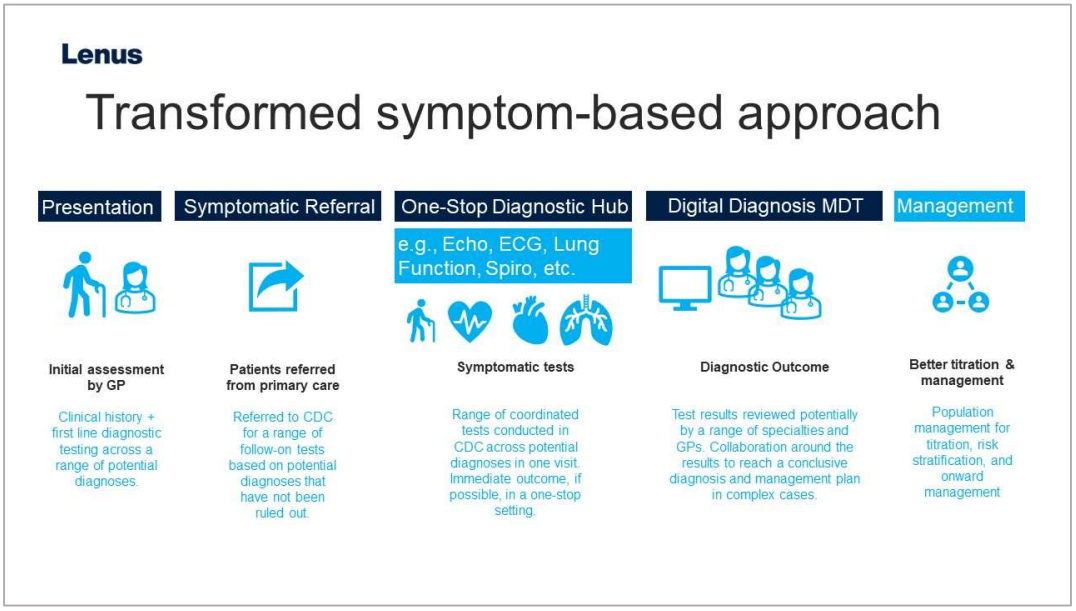


Figure 4. Transformed symptom-based pathway

## Conclusions

While investment in improved breathlessness diagnosis processes is welcome, there is the opportunity to extend the benefits through the use of Digital Diagnostic Pathway Tools to transform how diagnostic journeys, and the resultant testing approaches, are coordinated. These tools not only enable better sharing of data and management of patients in the pathway, but also offer a route to implement a comprehensive, symptom-based testing approach to transform diagnostic journeys, reduce waits, and improve onward care.

By implementing a small number of cost-effective blanket tests deployed locally, potential conditions can be rapidly ruled out and ensure that the patient is referred correctly to the right follow-on tests for diagnosis. These can be coordinated in one-stop shop CDCs, while diagnosing clinicians can virtually collaborate around the data to provide comprehensive diagnosis.

Finally, the data generated by Digital Diagnostic Pathway Tools can be leveraged to support equitable and efficient onward management of the most burdensome chronic conditions by developing local population-based registries for proactive and personalised care initiatives.

Lenus Health is currently working with systems in the Midlands and the North-West of England to configure our Digital Diagnosis Pathway Tool to support transformed breathlessness pathways via the CDC pathway development fund.