

Counting the Cost: The Hidden Burden of Late Pulmonary Arterial Hypertension Diagnosis



MSD has funded an analysis of publicly available data to understand the potential savings that could be achieved through the expedited diagnosis of Pulmonary Arterial Hypertension.¹

This infographic and the analysis it is based upon have both been fully funded by MSD.

Unexplained breathlessness presents a significant challenge within our healthcare system, often leading to delayed or incorrect diagnoses due to poor symptom recognition.²

Breathlessness is a primary symptom of pulmonary arterial hypertension (PAH) – a subset of pulmonary hypertension (PH) – a rare disease which is often left undiagnosed for years due to its non-specific symptoms.³ Delays in diagnosis not only worsen outcomes and leads to greater treatment burden for patients⁴, but also generate considerable costs for the NHS through repeat consultations and hospital admissions.⁵

PAH is a rare and debilitating disease that causes the arteries between the heart and lungs to constrict and narrow.⁶ A PH diagnosis is a life-changing event for those living with the condition and their loved ones.⁷



In 2023/24, 4,626 people had an active referral for PAH in the UK.⁸



For adults with PAH, the survival rate is approximately 50% five years post-diagnosis.⁸



Detection and time to diagnosis of PAH remains a considerable challenge in the UK, partly due to its rarity and non-specific symptoms (i.e. breathlessness).³

In addition to the significant personal and family impact, PH (including PAH) generates significant costs for the NHS through repeat consultations and hospital admissions,⁵ and to the wider economy through loss of workforce productivity. An optimised breathlessness pathway utilising Community Diagnostic Centres and the appropriate referral to relevant specialist centres of excellence may enable more accurate and timely diagnosis of PAH, as well as other conditions such as heart failure and other respiratory diseases, and lead to more accurate entry into the right treatment and care. The diagnosis of PAH could be considered as a litmus test for the optimal management of breathlessness.

Current typical diagnostic pathway for suspected PAH

6 MONTHS

Current State of Play: almost half of patients wait over a year from first experiencing symptoms to getting a diagnosis of PAH.⁹

Patient experiences symptoms such as shortness of breath

In 12 months of first experiencing symptoms, 30% of people with PAH did not visit a GP⁹

GP contact

Various tests may be conducted to identify the issue (e.g. electrocardiogram, chest x-ray, CT scan, MRI scan). 40% of PAH patients have 4+ GP visits before receiving a PAH diagnosis⁹

Secondary care

Almost half of PAH patients receive a misdiagnosis.¹⁰ Symptoms continue to worsen and the cycle of investigation may extend for two years; for 20% of patients it takes 3 years or longer⁹

Specialist centre

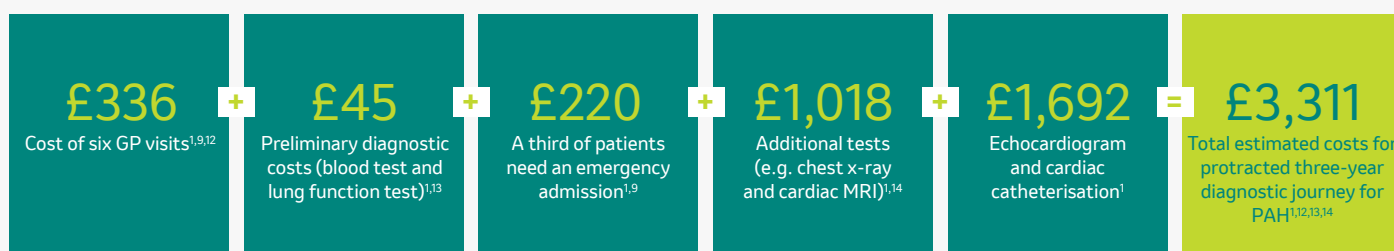
At the specialist centres, patients undergo diagnostic investigations for PAH including right heart catheterisation⁹

PAH diagnosis confirmed

Delays in diagnosis worsen outcomes and limit treatment options for patients^{3,4,11}

With the current diagnostic pathway, patients may face considerable delays and worsening symptoms leading to greater costs to the health system and a substantial impact on quality of life.

Estimated diagnostic costs of protracted diagnostic pathway*



*This is an estimated cost based upon a theoretical protracted patient journey from symptoms to diagnosis. It is based upon an estimated three-year timeline, which includes six GP visits, preliminary diagnostic tests, emergency admission and further testing at specialist centres. Data has been derived from literature estimates from NICE (2015), UH Bristol NHS Foundation Trust (2015) and the King's Fund (2024). Additional details were derived from the MSD funded analysis.¹

Scenario one: earlier diagnostic pathway for suspected PAH

Theoretical diagnostic pathway: patients receive a diagnosis in six months from symptom onset

6 MONTHS

Patient experiences symptoms such as shortness of breath

GP contact

Timely clinical investigations to identify risk of PAH and enable expedited referral

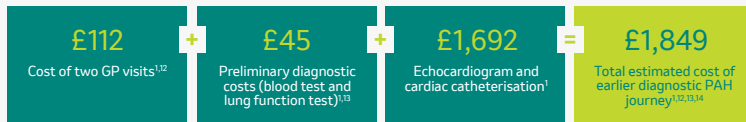
Specialist centre

At the specialist centres, patients undergo diagnostic investigations for PAH including right heart catheterisation⁹

Diagnosis: condition is classified depending on severity and treatment is initiated

Symptoms continue to exist but are potentially more manageable due to lower severity and treatment

Estimated costs of earlier diagnostic pathway*



*This is an estimated cost based upon a theoretical six month timeline from symptom onset to diagnosis which includes two GP visits, preliminary diagnostic tests and further testing at specialist centres. Data has been derived from literature estimates from NICE (2015), UH Bristol NHS Foundation Trust (2015) and the King's Fund (2024). Additional details were derived from the MSD funded analysis.¹

With an earlier diagnosis, patients may be able to continue working for longer

Scenario two: rapid diagnostic pathway for suspected PAH

Theoretical diagnostic pathway: patients receive a diagnosis in two months from symptom onset

2 MONTHS

Patient experiences symptoms such as shortness of breath

GP contact

GP refers patient to the breathlessness pathway which may include access to CDCs, enabling earlier identification of PAH risk and expedited referral

Specialist centre

At the specialist centres, patients undergo diagnostic investigations for PAH including right heart catheterisation⁹

Diagnosis: condition is classified depending on severity and treatment is initiated

Symptoms continue to exist but are potentially more manageable due to lower severity and treatment

Estimated costs of rapid diagnostic pathway*



*This is an estimated cost based upon a theoretical two month timeline from symptom onset to diagnosis, which includes one GP visit, referral into the breathlessness pathway which assumes the following tests were conducted; spirometry, FeNO, chest x-ray, blood and lung function tests. Data has been derived from literature estimates from NICE (2015), UH Bristol NHS Foundation Trust (2015) and the King's Fund (2024). Additional details were derived from the MSD funded analysis.¹

Conclusion

By prioritising earlier diagnosis of PAH, this can potentially have sizeable benefits not only to the health system, but also for patients' quality of life.

Creating a diagnostic pathway which optimises local services to diagnose and manage breathlessness can not only improve care for PAH, but deliver system wide benefits for other respiratory conditions.

The estimated savings show the impact of implementing an earlier diagnosis pathway for newly diagnosed PAH patients. The yearly rounded average of new PAH cases (N = 600) was taken as a sample size.

IN PRACTICE:

The Queen Victoria Hospital NHS Foundation Trust piloted an approach utilising the breathlessness pathway across a range of conditions with unexplained breathlessness and saw a 63% reduction in patient wait times from referral to treatment for breathlessness compared to the 18-week national target (46 days compared to 126 days).¹⁶

The full analysis, covering several diagnostic pathway scenarios for PAH as well as treatment costs, can be made available upon request.¹

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Healthcare system: Savings from avoided diagnostic procedures

- > Avoided GP attendances = £130k¹
- > Avoided emergency attendances = £160k¹
- > Avoided additional diagnostic tests = £161k¹

*The healthcare system savings are an estimate modelled on scenario one. These estimates have been sourced from Armstrong et al. (2019).⁹