ASTHMA+ LUNG UK
CYMRU

THIS IS LIFE+ BREATH

Why the Quality Statement for Respiratory Disease needs to be implemented urgently

November 2024

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Wales remains the worst nation in Western Europe for respiratory deaths.

Executive summary

November 2024 marks two years since the publication of the Welsh Government's *Quality Statement for Respiratory Disease* (2022), which contains 23 attributes intended to give health boards a measure for what constitutes good quality respiratory care[1].

Asthma + Lung UK Cymru feel that this document does not go far enough to give patients the quality of care they need to thrive with lung conditions and falls far short of our UK-wide goals for lung health. In addition, the current quality attributes do not come with key performance indicators, meaning that we are unable to identify if they are being achieved across Wales. Respiratory care remains an underfunded discipline, despite so many emergency hospital admissions being attributed to respiratory conditions.

1 in 5 people in Wales have a lung condition and respiratory disease remains in the top three causes of death in our nation. The cost to Wales is a staggering £772 million per year, due to direct and indirect costs of lung conditions[2].

At the time of writing, Wales remains the worst nation in Western Europe for respiratory deaths. We are second only to Turkey in the whole of Europe[3].

With respiratory care in Wales underperforming to such an extent, we feel that an improvement plan is needed to give far greater detail, key performance indicators and ambitious targets for quality care.

Notwithstanding the need for an improvement plan, many of the quality attributes have not been adopted across Wales, leading to inconsistent and inadequate respiratory care across the country. For example, under 40% of COPD patients admitted to hospital receive a respiratory review within the target time of 24 hours[4], innovative treatments for asthma are not being used to their full extent, and diagnosis for both asthma and COPD remains an expensive process of trial, error and wasted inhalers.

Recommendations

1. A comprehensive improvement plan for respiratory care in Wales similar to that available for cancer.

2. Welsh Government need to prioritise the diagnosis of respiratory patients by providing a spirometry recovery fund of £1.1 million over the next two years.

3. General practice needs to prioritise lung conditions, steadily increasing the proportion of people with asthma and COPD receiving good year-round basic care, so that the majority of people receive it by the end of the next Senedd.

4. Expand community respiratory teams to prevent hospital admissions and reduce winter pressures.

5. Increase access to pulmonary rehabilitation (PR) for all those eligible - develop All-Wales standards, sign up to the Pulmonary Rehabilitation Services Accreditation Scheme (PRSAS), develop an opt-out direct referral system and utilisation of digital PR.

Living with a lung condition in Wales

In our report *Saving Your Breath: How better lung health benefits all of us in Wales* (2023)[5], we revealed that lung disease is the third biggest killer in Wales, representing around 15-16% of all deaths prior to the pandemic.

In the most disadvantaged areas of Wales, people with COPD are five times more likely to die and those with asthma are three times more likely to die than those in the richest areas.

Lung disease in Wales costs NHS Wales £295 million in direct costs each year, representing 1.3% of total NHS Wales expenditure . It causes wider reductions in productivity due to illness and premature death totalling £477 million a year, leading to an overall impact of £772 million on the Welsh economy. Many lung conditions can be prevented by reducing exposure to triggers such as poor housing, tobacco, air pollution and occupational hazards such as asbestos and chemical fumes.

The avoidable mortality rate is the number of deaths that could be avoided either by preventing disease or through effective healthcare. This has declined by 4% for respiratory disease in the last 20 years, whereas cardiovascular disease has improved by 56% in Wales[6].

Other systemic factors such as child poverty and the barriers to living a healthy lifestyle, such as obesity, food access and poor mental health, also contribute to the avoidable exacerbators of respiratory disease.

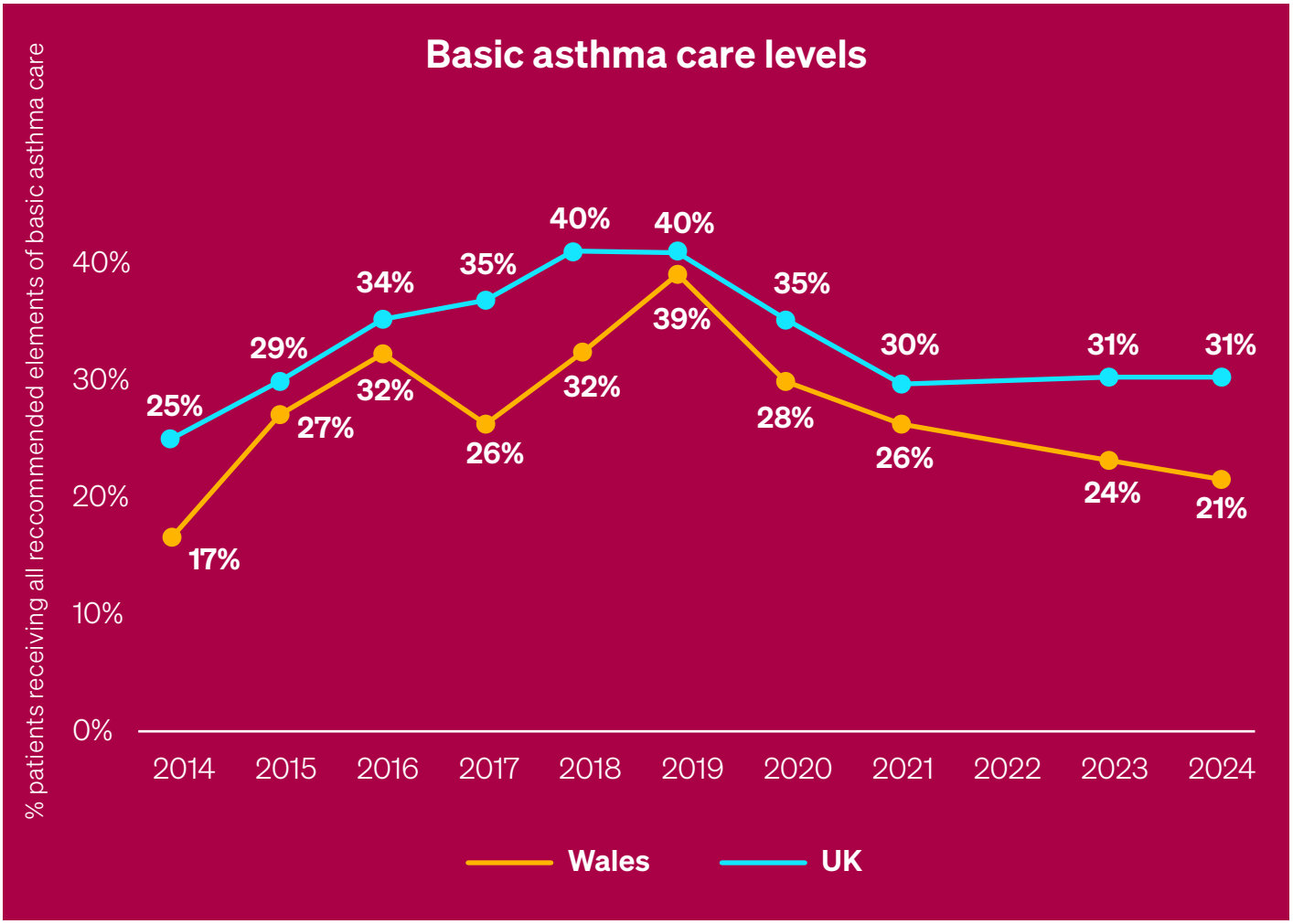
In 2024, Wales is still reeling from the cost-of-living crisis, and the current struggle to heat homes puts added strain on the lungs of those living with these conditions.

In our *Life with a lung condition* (2024) survey, 43% of those with asthma said they found it harder to buy food because of the cost of living crisis, while 52% of respondents reported difficulty paying their energy bills[7]. This in turn directly affects people's health. Our survey also found that of those with an income less than £20,000 annually, 70% feel their lung condition has worsened in the past year, compared to 54% of those with an income above £70,000 annually[8].

Added complexity comes from the overall health of those with a lung condition. 7 out of 10 of our survey respondents with asthma reported having another health condition. Many also suffer with poor mental health as well as other comorbidities, meaning that specialised treatment may not address all of a patient's health concerns.

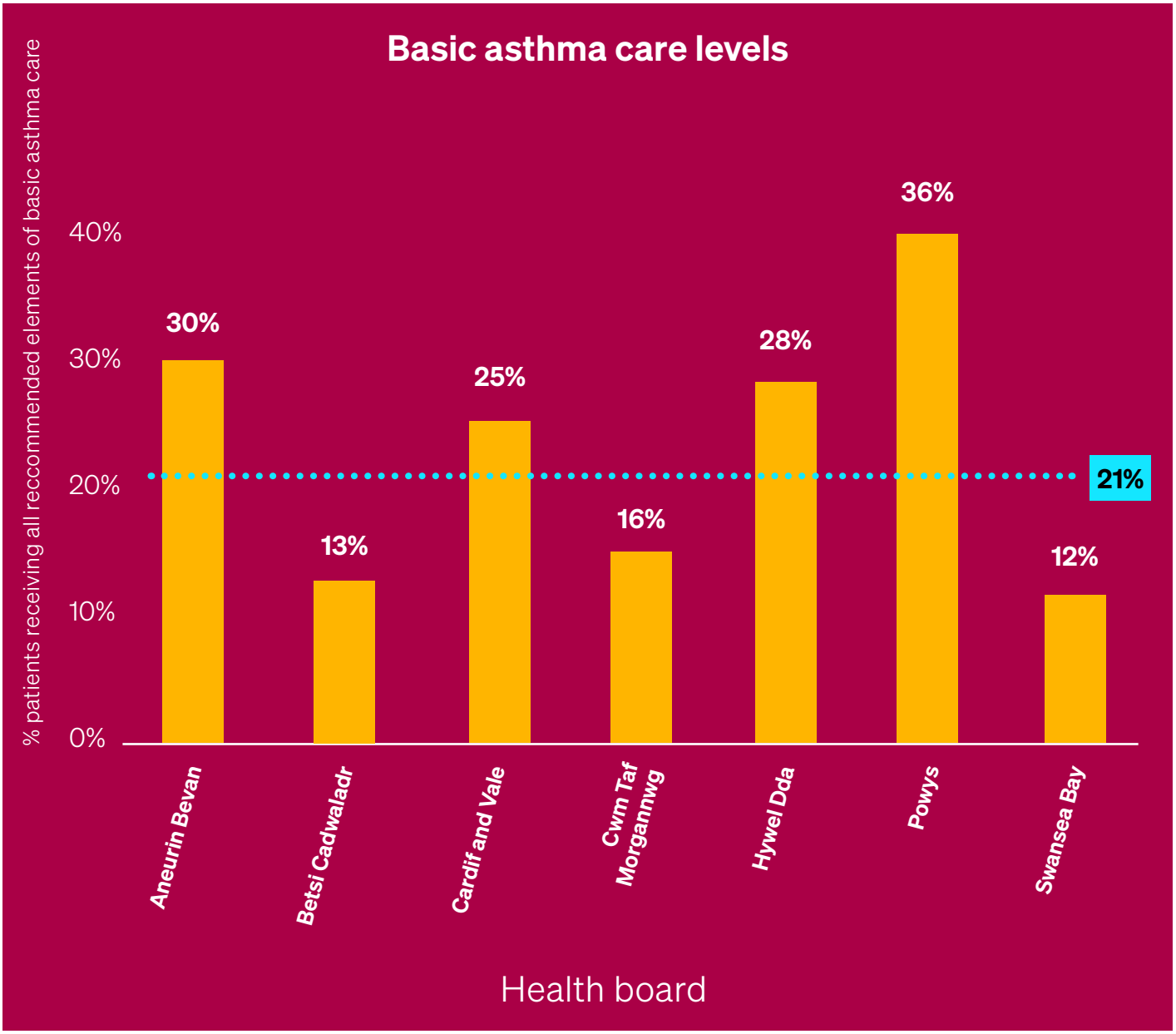
Unfortunately, we still find ourselves in a vicious cycle of late diagnosis, inequitable access to treatments, and a lack of support for patients. This leads to a high number of emergency admissions, substantial costs to the NHS and often, a radical reduction in a patient's quality of life – all of which could be prevented with early intervention. As the patient leaves hospital, this cycle then starts again.

The survey showed that basic asthma care levels are not being received, even less so than across the rest of the UK.



From a high of 39% of people with asthma in Wales receiving the three components of basic care (an annual review, inhaler technique and an annual action plan), the percentage has fallen year on year so that now only 21% of people receive basic care. This is in contrast to UK levels which have reached a plateau following the pandemic.

There is variation between health boards, showing that best practice is not being adhered to. This could also be attributed to health inequalities across Wales, where more deprived areas have higher rates of respiratory disease, disproportionately increasing workload.

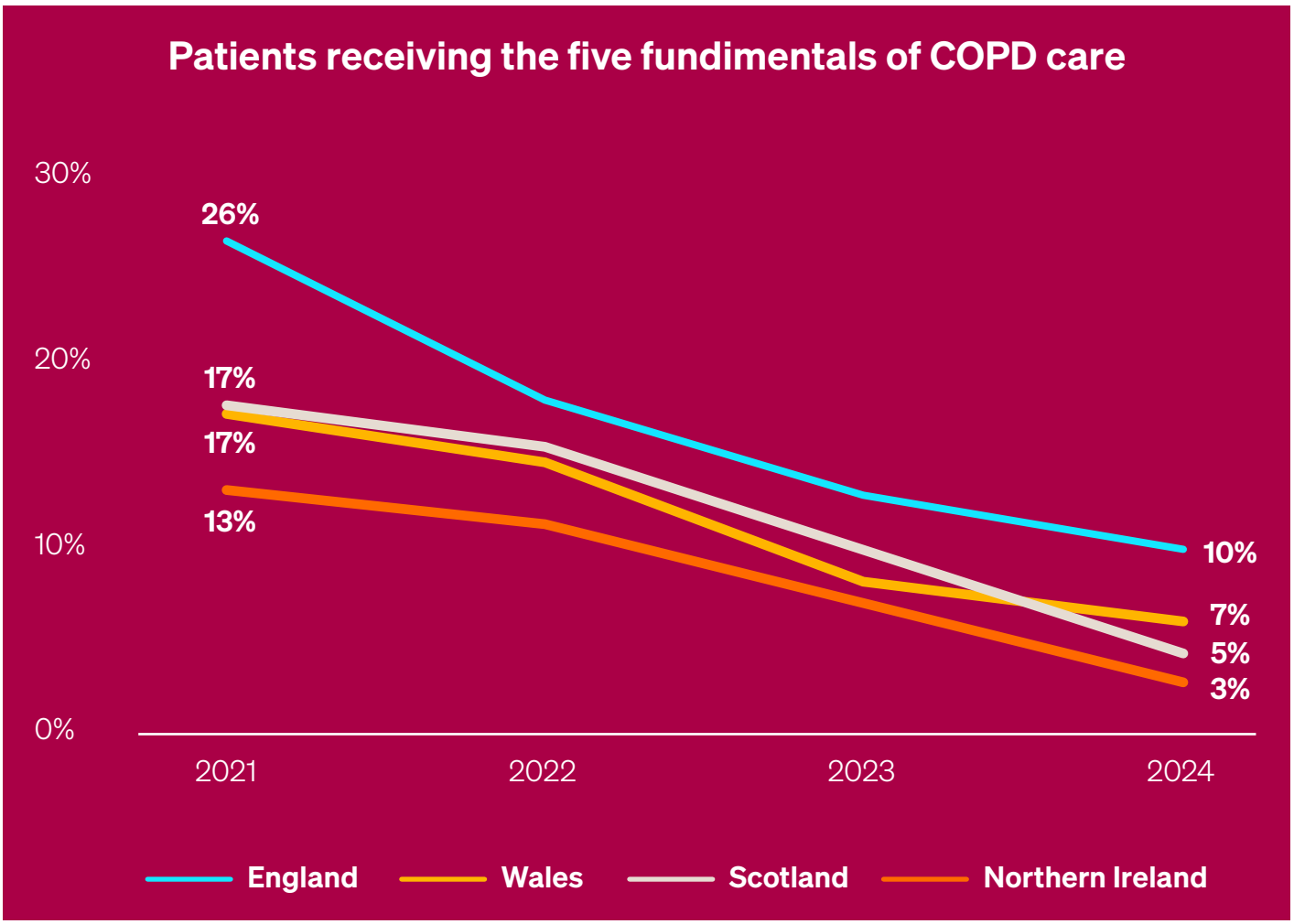


Chronic obstructive pulmonary disease (COPD) is the name for a group of lung conditions which make it more difficult to breathe air out of the lungs, due to a permanent narrowing of the airways and destruction of lung tissue. COPD includes long-term (chronic) bronchitis and emphysema. In Wales there are approximately 74,000 people with a diagnosis of COPD.

The five fundamentals of COPD care, as recommended by NICE, are:

- **offer treatment and support to stop smoking**
- **offer pneumococcal (pneumonia) and influenza vaccinations**
- **offer pulmonary rehabilitation (PR) if indicated**
- **co-develop a personalised self-management plan**
- **optimise treatment for comorbidities.**

COPD care has seen an even steeper decline than asthma in Wales, falling from a disappointing 17% of people receiving all five fundamentals to only 7% in 2024:



1 in 5 people in Wales have a lung condition.

Quality statements and the clinical network

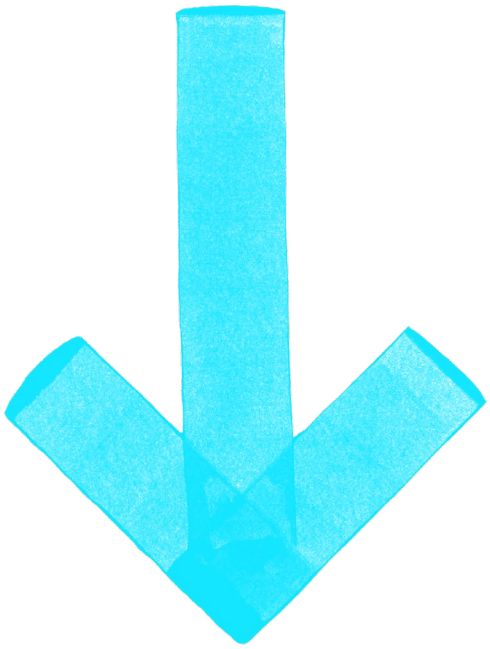
In 2018, the Welsh Government published *A Healthier Wales: Our plan for health and social care*[9]. In this plan, the Welsh Government announced that it would move away from the production of delivery plans for health, and instead would produce a series of quality statements.

These promised to "describe the outcomes and standards we would expect to see in high quality, patient focussed services... These [quality statements] will set out ambitions to be delivered consistently across Wales."

Part of the mechanism for achieving the goals set out in *A Healthier Wales* was the establishing of the NHS Wales Executive, a body intended to provide oversight to health boards and to ensure consistent communication between Welsh Government and the entities which make up the NHS. The NHS Wales Executive was established in 2023 and part of its makeup includes clinical networks, which are specific to conditions, groups of conditions or areas of medicine. The Respiratory Clinical Network, established in 2023, has taken over the work and funding of the Respiratory Health Implementation Group (RHIG).

The *Quality Statement for Respiratory Disease* was produced in November 2022. It is a list of 23 quality attributes which correspond to themes which each health board's respiratory service should aspire to achieve[10].

The quality statement therefore prescribes that respiratory services across Wales should be:



Equitable

1. The Respiratory Health Implementation Group develops national datasets to support clinical decision making and improve local planning of respiratory disease services for adults and children and young people.

2. The Respiratory Health Implementation Group develops and maintains national guidance, pathways and tools (including PROMs) to support health boards deliver consistent and excellent respiratory disease care.

3. Health boards provide (or commission) specialist multi-professional teams, competent in the management of adult chronic respiratory disease (including tuberculosis, interstitial disease, COPD, asthma, sleep disordered breathing, and the delivery of oxygen therapy), that are appropriately resourced to meet the needs of their population.

4. Health boards commission (or provide) regional specialist multi-professional teams competent in the management of chronic respiratory disease among children and young people

Safe

5. Health boards, as appropriate, admit patients with more severe single organ respiratory failure to a respiratory support unit (RSU), or intensive care unit, with staffing and equipment that meets national guidelines.

6. Health boards provide (or commission) difficult-asthma services for people with severe or uncontrolled disease, which collaborate at national level to ensure consistency of provision and appropriate access to biologic therapy.

7. Health boards take part in national clinical audit for respiratory disease and apply quality improvement methodology and national quality improvement resources in response to the findings.

8. All patients considered for long-term oxygen therapy at home should have a standard assessment in line with British Thoracic Society guidance.

Effective

9. Adults affected by chronic respiratory disease, where appropriate, receive routine care and review in primary and community care by a healthcare professional who is competent in the management of the patient's respiratory condition.

10. People with respiratory disease, and parents of children with respiratory disease, who use tobacco should be given brief cessation advice, offered Nicotine Replacement Therapy, and referred to smoking cessation services.

11. People with chronic respiratory disease are offered their routine vaccinations to reduce their risk of exacerbation and hospitalisation.

12. Health boards and trusts collaborate with academic and industry partners, such as Respiratory Innovation Wales, to accelerate research activity and innovation in respiratory medicine.

13. Health boards have a nominated clinical and corporate lead for tuberculosis and a local plan for prevention and control, to ensure services can deal with complex case management and respond to any incidents or outbreaks.

Efficient

14. People presenting multiple times to hospital with airways disease are supported by an appropriate member of a multi-professional team to improve disease control and reduce their risk of further unscheduled care admissions.

15. New COPD patients, and those already on a COPD register, have coded evidence in the clinical record of spirometry, performed by an appropriately trained healthcare professional.

16. New asthma patients, and those already on an asthma register, have coded evidence of disease according to the national guideline.

17. Medicine usage reviews support individualised and appropriate changes in prescribing practice, increasing the prescribing of lower global warming potential inhalers as a percentage of total inhaler prescribing and reducing the use of SABA and long-term oral steroid prescribing.

Person Centred

18. Spirometry should be available to patients over the age of 12 in primary or community care and results should be available to all relevant clinical teams through the Welsh Clinical Portal and independent contractor systems.

19. Patient apps are offered to all patients with asthma and COPD – or parents of children with asthma – as a digital patient self-management plan.

20. Provide access to appropriate rehabilitation opportunities, including social prescribing, exercise referral and pulmonary rehabilitation services; and to peer-support groups, including from the third sector.

Timely

21. All patients admitted to hospital with a primary respiratory illness are seen by a respiratory specialist within 24 hours.

22. All patients requiring non-invasive ventilation receive it within two hours of arrival at hospital and, as appropriate, are managed in a respiratory support unit or intensive care unit.

23. Health boards and Trusts plan for seasonal variation in acute respiratory exacerbations and provide rapid access, community-based services, to avoid unnecessary admissions.

The quality statement contains positive aspirations, but without an implementation plan, it is difficult to see how change will be delivered within health boards. The statement contains the 'what' and 'why' but leaves the 'how' to individual health boards.

Since *A Healthier Wales* (2018) was published, we have witnessed the most dramatic rise in respiratory deaths in the form of the COVID-19 pandemic, with Long COVID joining the ranks of chronic conditions affecting the lungs of the people of Wales. Yet the quality statement has been produced without guidance for struggling health boards, without a road map and without measurable outcomes.

In 2023, the Welsh Government produced a cancer improvement plan[11], but has said it will not develop plans for other conditions. Respiratory conditions are insidious: they affect 1 in 5 of us and kill more people in Wales than anywhere else in Western Europe, and yet they do not inspire action to the same extent as other conditions. They are almost an accepted part of day-to-day life in Wales.

We believe the people of Wales deserve better, that they should be allowed to have higher expectations for their lung health, and that health boards need guidance of how to deliver the kind of respiratory service that the quality statement asks them to aspire to.

Therefore, Asthma + Lung UK Cymru is calling for a respiratory improvement plan to implement the quality statement.

Respiratory care remains an underfunded discipline.

Equitable

With health inequality across Wales being a huge contributor to poor lung health outcomes, the closer we can come to an equitable health service, the better.

Respiratory conditions, in particular, affect those from disadvantaged backgrounds who are more likely to find themselves exposed to both indoor and outdoor pollutants and may not have access to good quality warm housing. Exposure to pollutants and cold, poor quality housing can both cause, and worsen, lung conditions.

Our *Life with a lung condition* (2024) survey found that those on incomes below £20,000 were 3.5 times more likely to be in bad health than those with higher incomes, while outright homeowners were 2.5 times more likely to report good or very good health, than those who did not own their home outright.[12].

Therefore, it is imperative that an equitable service not only affords access to the same quality of services across the whole of Wales, but actively targets those from poorer backgrounds, whose symptoms and life chances following diagnosis may be considerably worse.

Data

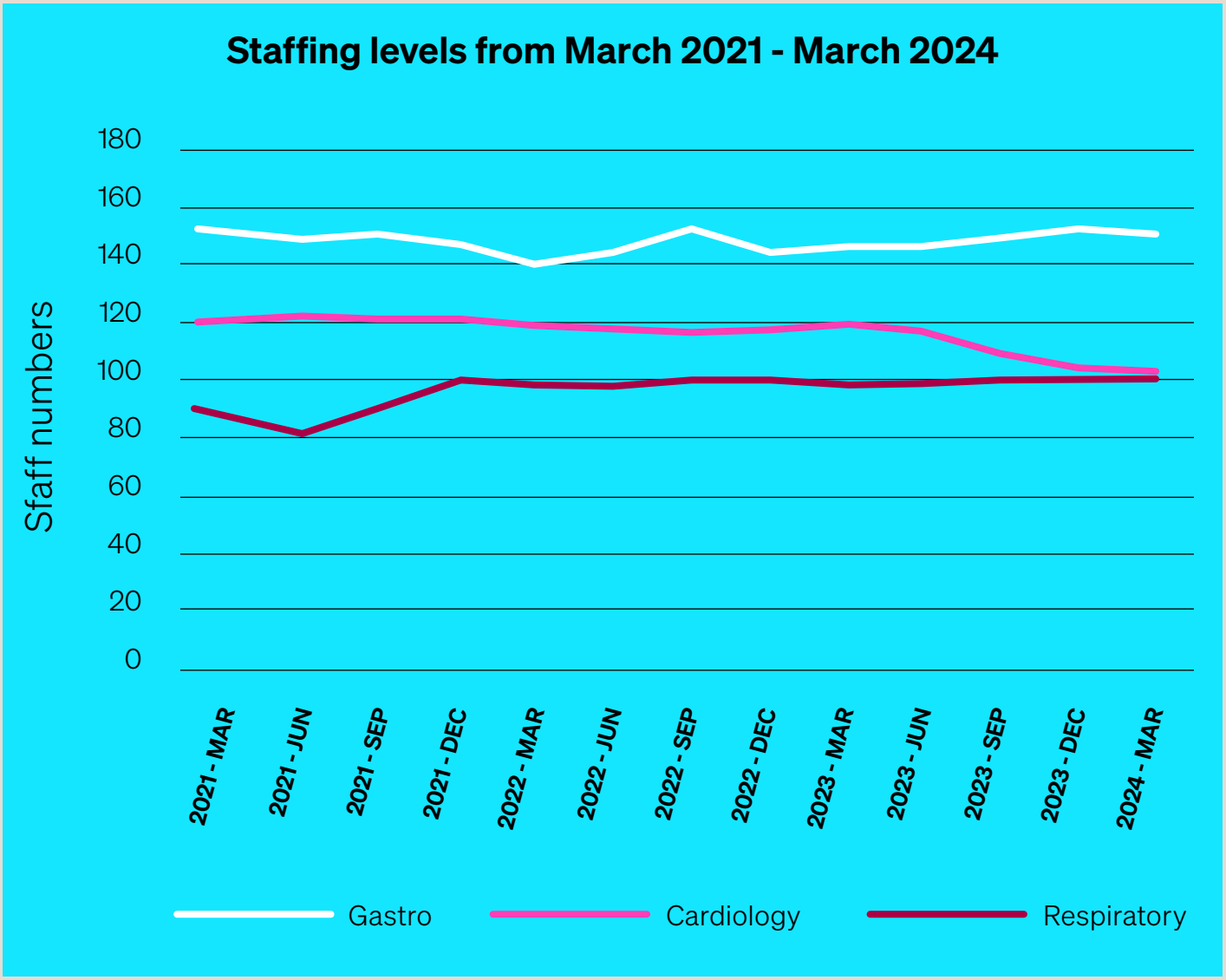
Wales suffers from a chronic lack of information about its patients and its services. Numbers are recorded across health boards, however without parity between what is collected, how it is collected and how it is organised for staff to use, it does not contribute to an equitable service. The quality of data is also questionable, with accurate coding not used consistently across the board. The NHS Wales Executive has committed to developing dashboards to give clear usable patient data across health boards which can be used to measure outcomes and set improvement targets, but this has not yet been produced.

Without knowing the current situation, the NHS in Wales cannot set targets for its improvement. We welcome the publication of these dashboards, to give a clear and consistent overview of the current state of respiratory care in Wales.

Workforce

Quality Statement attribute 3 commits health boards to provide or commission specialist multi-disciplinary teams competent in the management of all types of respiratory disease[13].

Compared to other in-patient services, the secondary care staffing levels have declined, compared with levels when the quality statement was published. Conversely, cardiology services have remained consistent, showing a disparity in investment and interest in respiratory care[14]. It is not possible to measure the numbers of staff working in the community as the data kept is highly generalised[15].



Health boards must invest in staffing levels for respiratory wards so inpatients can access the care they desperately need.

Staffing for pulmonary rehabilitation

Investing in staffing for specialist pulmonary rehabilitation (PR) in the community is a simple way of ensuring equitable services across Wales. PR is an effective treatment for a range of lung conditions, including COPD. It consists of exercise classes designed for people with long-term lung conditions, information on managing lung conditions and techniques to manage breathlessness. PR is one of the most cost-effective treatments for COPD, second only to smoking cessation, and as such the economic benefits of properly staffed services are staggering.

As reported in *Saving Your Breath* (2023), our analysis found that the expansion of PR would result in £7.7 million of direct NHS savings related to reduced exacerbations, as well as a reduction of 10,500 bed days, 3,500 of which would be saved over the winter period[16].

However, there is not equitable access to PR across the country. While each service must be tailored to its health board's geography and demographic, every service should have a fully staffed multi-disciplinary team (MDT) with access to occupational therapists, physiotherapists, exercise professionals, dietetic and psychological support.

Wales has not been part of the Pulmonary Rehabilitation Services Accreditation Scheme (PRSAS) until recently, when Swansea Bay University Health Board agreed became the first to trial it. Being part of this scheme would raise standards and improve quality, ensuring that every PR team would be able to access support, training, and mentoring, and improve the quality of services.

In order to maximise access to PR, the pathway should be adapted to include face-to-face services, virtual services and supported self-management. The use of digital tools for patients who are able to access devices could significantly reduce waiting lists, meaning that resources could be directed towards those patients who are not digitally literate.

A wealth of material including exercise videos, education and information about breathlessness is already available online and could be collated in such a way that it is useful for those patients who are able to access digital tools.

Used effectively, PR could be a cost-effective, high impact solution which makes a huge difference, not only to the symptoms of patients from all backgrounds, but to their quality of life. Health boards must invest in multidisciplinary teams to provide full PR services and reap the benefits.

Severe asthma

Severe asthma is a distinct condition which has an extremely significant impact on those affected. The *Saving Your Breath* (2023) report revealed that over half of those with severe asthma have uncontrolled symptoms, and many have to wait years before receiving the care they need to manage their condition[17]. This group also run the risk of serious side effects from extended periods on high dose oral corticosteroids[18].

The analysis carried out by Asthma + Lung UK and PwC found that costs for severe asthma patients were on average £2,477 per year, compared to £611 for non-severe asthmatics – just over 300% more. While severe asthma accounts for only around 5% of the total asthma population, this is still over 9,000 people in Wales.

Such is the severity of their symptoms that this group is estimated to account for at least half of all economic expenditure on asthma – around £74 million a year[19].

Quality Statement attribute 6 states that health boards should provide or commission severe asthma services[20]. Following a freedom of information request, Asthma + Lung UK Cymru has learned that the nature and quality of the data kept on this treatment varies from health board to health board.

Cwm Taf Morgannwg University Health Board and Swansea Bay University Health Board report that there are 132 and 160 patients in their health boards who have access to biologic therapy. While Aneurin Bevan University Health Board reports 815 admissions to hospital, with asthma cited as the reason for the admission. In Cwm Taf Morgannwg University Health Board and Cardiff and Vale University Health Board, there are 336 and 473 patients on the difficult asthma caseload or asthma follow-up cycle[21].

Since 2022, hospital prescribing data shows that only 39 doses of biologic therapy have been prescribed in hospitals and fulfilled in the community. This is because there are many barriers to this therapy: patients may not be able to reach hospital due to geography or lack of means.

Lisa Hall, a biomedical scientist from Magor, has severe asthma and is currently being prescribed tezepelumab. She struggles with her breathing daily and has many asthma triggers including cleaning products, hot weather and pollen:

“My asthma is very unpredictable. This year, ambulance control sent the air ambulance medics out to me. I was sent to A&E and treated in resus for six hours before being stabilised. It was just a normal day; I took my son to football training and my breathing quickly deteriorated. It’s very challenging and affects my day-to-life.

“I have been prescribed tezepelumab and it is going quite well, I haven’t been admitted to hospital since March. Things are frustrating at times, but you’ve got no choice but to carry on working things through.”

As shown above, biologic therapies can be life-changing for patients with severe asthma. However, health boards are not effectively measuring their success, nor are they investing in access to this therapy in the community. Health boards must innovate to bring this therapy out of hospital settings and into the community where it can be more widely accessed by severe asthma sufferers.

Safe

Quality Statement attributes 5 to 8 prescribe that respiratory services should be safe, with appropriate hospital admissions when required and consistent provision for the most severe disease, and with appropriate assessment and checks for therapies such as oxygen, before they are administered[22].

The National Respiratory Audit Programme

The National Respiratory Audit Programme (NRAP) undertakes primary and secondary care audits of respiratory services. England and Wales take part in the secondary care audit looking at 676 asthma, COPD and PR services. Wales is the only nation currently funding a primary care audit that is based on data from 359 general practices.

While it is clear that health boards are taking part in the audit, as prescribed by Quality Statement attribute 7, when reviewing the data, the NRAP standards are falling far below the desired best practice level.

For example, since January 2022, there were 11 months where the audit found that less than 10% of respiratory patients received a discharge bundle when they were sent home from hospital[23]. This included Winter 2023, when Welsh Government removed the mandate for packages of care, with senior NHS leaders declaring the system **"on a knife edge"** [24]. The announcement came just two months after the publication of the quality statement, indicating the attributes were far from being implemented effectively.

Studies show that, worldwide, mortality rates for those admitted to hospital with respiratory failure are among the highest[25]. Therefore, a package of care for these vulnerable patients is crucial to ensuring their continued safety when they leave hospital. However, in the majority of cases, this is not happening.

Currently in Wales and across the UK, pilots are taking place where patients can be discharged onto 'virtual wards'. Known as early supported discharge, patients can be sent home but monitored remotely, as if they were still in hospital, with a combination of virtual monitoring and home visits[26]. This gradual discharge process has been shown to reduce the risk of infection, make patients feel more comfortable and ultimately reduce the risk of readmission[27].

Rolling this out across Wales would make beds available for those patients most in need and allow patients to be sent home with support. This is one example where innovation can reduce workload and improve patient outcomes.

Basic asthma care

While not part of the 'safe' requirements, it seems that even basic asthma care is falling below basic standards. NRAP's Primary Care Audit 2021-2023 shows that only 27.9% of adults with asthma and only 24.1% of children with asthma receive an asthma action plan[28]. This action plan is key to keeping asthma patients safe and it gives guidance on how to manage symptoms and prevent potentially life-threatening asthma attacks.

The action plan should be tailored to each person and note their specific triggers, such as allergens or exercise. Without this guidance, patients are left to manage their symptoms alone, which is the antithesis of safe care.

As shown in the data from the *Life with a lung condition* (2024) survey, basic levels of care for both asthma and COPD in Wales have declined (see the 'Living with a lung condition in Wales' section). Therefore, the quality statement is not having the desired effect.

There needs to be an emphasis on doing the basics well in order to prevent hospitalisations and unnecessary illness, which create more work and expense for the NHS later down the line.

Effective

Smoking cessation

As shown in *Saving Your Breath* (2023), tobacco smoke is still the largest cause of preventable illness and death in Wales, with two out of every three smokers dying of a smoking related illness. While smoking rates have declined, 12.6% of people in Wales still smoke[29].

Smoking is directly correlated to deprivation, with those in the most deprived areas over three times more likely to smoke than those in the least deprived[30].

In 2021, the Department of Health and Social Care in England showed that people who were raised in households where the parents smoked were four times more likely to start smoking themselves[31]. This shows how insidious smoking can be in our communities and how crucial it is to break this cycle and give meaningful support to those caught up in it.

Quality Statement attribute 10 rightly prescribes that those who smoke should be encouraged to use smoking cessation services[32]. Smoking cessation is the second most cost-effective means of preventing lung conditions in those who smoke and minimising the effects of lung conditions in smokers who are already suffering[33].

Numbers of people in Wales taking up smoking cessation services remain small, with only 16,441 people taking up smoking cessation services in 2023/2024[34]. This is an increase from 9,600 in the previous financial year, however compared to the number of admissions for respiratory disease, particularly during the winter (see the 'Timely' section below), these numbers are very low. We would like to see increased public awareness of these services in tandem with the emphasis on stopping young people taking up smoking. The legacy impact of high smoking prevalence in Wales is being felt by the NHS and will continue to be if this is not addressed.

Vaccinations

While smoking cessation is the second most cost-effective measure to treat respiratory conditions, routine vaccination remains the first[35].

Quality Statement attribute 11 prescribes that **"people with chronic respiratory disease are offered their routine vaccinations"** [36].

It is clear routine vaccinations are being offered across Wales, with the model of vaccination centres adopted during COVID-19 remaining long after restrictions were lifted. However, perhaps due to vaccine fatigue, numbers of eligible people with lung conditions taking up the vaccine have declined since the publication of the quality statement.

Public Health Wales report that: **"Chronic respiratory disease was recorded in 7.6% of patients aged six months to 64 years, of whom 44.3% were immunised against influenza (Figure 4.2.5, Appendix Table A2), ranging by health board from 39.8% (Cardiff and Vale University Health Board) to 48.8% (Powys Teaching Health Board). Across Wales, 57.4% of those with COPD were immunised against influenza, whilst 43.4% of those with asthma and 49.8% of those with non-asthma non-COPD respiratory were immunised against influenza according to NHS Wales figures for the winter period 2022/23."** [37]

"Chronic respiratory disease was recorded in 7.7% of patients aged six months to 64 years, of whom 40.7% were immunised against influenza (Figure 4.2.5, Appendix Table A2), ranging by health board from 37.3% (Cardiff and Vale University Health Board) to 46.2% (Powys Teaching Health Board). At Wales level, 50.9% of those with COPD were immunised against influenza, whilst 40.1% of those with asthma and 43.9% of those with non-asthma non-COPD respiratory were immunised against influenza according to NHS Wales figures for winter period 2023/24." [38]

The Welsh Government must invest in further campaigns to highlight the importance of people accepting their annual vaccinations to prevent winter hospital admissions.

Pulmonary rehabilitation

Although not included in this section of the quality statement, pulmonary rehabilitation (PR) is one of the most effective and cost-effective treatments for symptoms of breathlessness – but is not being used effectively across Wales.

According to the *Life with a lung condition* (2024) survey, only 40% of people with COPD received PR, and the most recent 2024 NRAP Primary Care Audit showed that just 13% of COPD patients had been referred for PR. While this is an improvement on the 2021 audit's 5.6%, these numbers are staggeringly low given the benefits.

Our *Saving Your Breath* (2023) report showed that PR could save the NHS in Wales £7.7 million if referral rates were increased to 80% and completion rates within the referral population to 50%[39].

Research and innovation

Quality Statement attribute 12 states that: **"Health boards and trusts collaborate with academic and industry partners, such as Respiratory Innovation Wales, to accelerate research activity and innovation in respiratory medicine."** [40]

We welcome recent news that there have been developments in this area. In September 2024, Health Research and Innovation Wales reported that the Wales Centre for Primary and Emergency Care Research had discovered a link between resolved childhood asthma and increased risk of respiratory infections[41].

In 2023, AstraZeneca signed up to a charter with Welsh Government, Swansea University and Life Sciences Hub to promote health innovation in Wales, citing the lung cancer screening and asthma diagnosis as two of its target areas of research[42]. We look forward to seeing progress with this innovation. However, there seems to be a gap in the ambitions of Welsh Government and the quality of care currently being delivered.

Efficient

Diagnosis

For the two most prevalent lung conditions, asthma and COPD, it is rare to see a formal diagnosis using methods recommended by NICE guidelines.

For many patients, diagnosis is simply a case of trial and error, which is far from the efficient and targeted care to which the quality statement aspires.

COPD

Quality Statement attribute 15 states: **"New COPD patients, and those already on a COPD register, have coded evidence in the clinical record of spirometry, performed by an appropriately trained healthcare professional."** [43]

NICE Guidelines state that COPD should be diagnosed based on the presentation of symptoms, such as breathlessness, and should be confirmed using spirometry[44].

However, in Wales, the recent NRAP Primary Care Audit observed that just 21.4% of patients with COPD had any post-bronchodilator spirometry code [spirometry test] in the last two years[45]. Health boards must invest in access to timely and accurate spirometry. This would ensure appropriate treatment for COPD and ultimately ensure that unnecessary costs to the NHS are not incurred.

Asthma

Quality Statement attribute 16 states: **"New asthma patients, and those already on an asthma register, have coded evidence of disease according to the national guideline."** [46]

The numbers having an objective measurement for asthma are slightly higher than those with COPD. 39.8% of children with asthma had a recorded measurement, such as a spirometry reading, while 54.4% of adults had a recorded measurement[47].

Ella Davies, from Cardiff, found her asthma diagnosis confusing and overwhelming, unsure of how to manage her condition or what steps to take next:

“My experience with being diagnosed for asthma was confusing and time consuming, involving many visits to GP practices over months. I initially visited my GP for a separate matter, but she noticed my breathing, took my peak flow and suggested I had asthma. I was trialled on inhalers, although I was later found to have pneumonia at the time. I trialled a series of other inhalers over several months and, I received a formal diagnosis of asthma. Unfortunately, I haven’t undergone the recommended tests to diagnose asthma, so there will always be a doubt in my mind about my diagnosis.”

Primary care-delivered diagnosis

Since the beginning of 2023, we have seen health boards begin to trial new spirometry services for those suspected of having COPD. However, these centres, such as the Community Spirometry service in Cardiff and Vale University Health Board[48] and the Rapid Access Lung Clinics in Hywel Dda University Health Board[49], have not yet reached the necessary scale to provide an accurate diagnosis to all patients who desperately need one.

Most GP practices are not offering spirometry, and many have nowhere to refer patients for accurate diagnosis[50]. When we factor in poor access to public transport, particularly in more rural parts of Wales, with the likelihood that these patients’ mobility will be impacted by their breathing difficulties, it is clear that more needs to be done to ensure that access to accurate diagnosis is as far-reaching as lung disease itself.

In *Saving Your Breath* (2023), we found that if 40% of eligible patients took a spirometry test in primary care it would save the NHS £3 million in direct cost savings due to reduced COPD exacerbations and a reduction of 3,420 hospital bed days, including 1,163 winter bed days. We estimate that, in addition to the 74,000 COPD patients in Wales, there may be an additional 30,000[51] people who are undiagnosed and therefore missing out on vital treatment.

NHS England states that spirometry tests cost up to £56.88 per test[52]. At this price, £1.1 million over two years would deliver 20,000 tests. This would lead to a significant reduction in the backlog of people waiting for tests and embed spirometry back in the community.

The poorest COPD patients are 4.7 times more likely to die than the richest. We would therefore recommend focussing this fund on areas of deprivation[53].

Person-centred

Quality Statement attribute 19 prescribes that **"patient apps are offered to all patients with asthma and COPD – or parents of children with asthma – as a digital patient self-management plan."**

In 2022, we published *Raising the bar – Improving asthma care in Wales* which revealed:
"In November 2022, ICST conducted a survey sent out to 10,000 current app users receiving responses from 370 of them... Initially respondents are asked prior to downloading the app, how well-managed their condition was. The average was 6 out of 10 and it rose to 7 out of 10 for people using the apps.

"When asked to compare how often they are visiting their GP now versus how often they would visit before they used the app, 22.28% of people said the number of visits had reduced.
"The evaluation showed that people who had used the app for over six months were more likely to have seen a benefit, with GP visits decreasing by 35.71% and hospital admissions down by 18.57%." [54]

In the Senedd Health and Social Care Committee's review of the Welsh Government's Draft Budget 2023-2024, the committee cited the apps as a preventative resource and questioned funding for them.

The then Health Minister noted:
"...the COPD apps were developed as part of the respiratory health delivery plan, by the respiratory health implementation group, so that funding came to an end after eight years, as has the procurement arrangements for that respiratory toolkit, and that includes the COPD apps. At the moment, the health boards' executives are arranging for an evaluation of that toolkit, to determine whether that should be reprocured." [55]

The apps are an excellent resource to support patients and parents and can help patients to lead full, active and healthy lives despite having a lung condition.

Health boards and Welsh Government must ensure that there is clear messaging endorsing the apps and encouraging their use for patients able and willing to do so.

Pulmonary rehabilitation (PR) and social prescribing

Quality Statement attribute 20 states that health services should **"provide access to appropriate rehabilitation opportunities, including social prescribing, exercise referral and pulmonary rehabilitation services; and to peer-support groups, including from the third sector."**[56]

However, this does not go far enough to ensuring that PR and social prescribing are used to their full potential. Implemented broadly, PR could reach even more of the population and greatly effect communities where lung conditions are one of the most prevalent inhibitors to quality of life. The supervised exercise element of the programme helps patients to understand how out of breath they should be when exercising and helps to condition the lungs to improve breathing. Combining this with education, including information on inhaler technique, how to use medication effectively and other information on lifestyle changes, makes this a supremely effective treatment. However, throughout Wales, there is inconsistent provision of PR services, with some areas not referring due to lack of staffing and provision, while in other areas, waiting lists are up to four years for similar reasons[57].

Trystan Roberts, 48, from Powys, discovered new strength through PR after being diagnosed with COPD:

“I struggled with my breathing for around seven years before also being diagnosed with COPD. A nurse recommended pulmonary rehab; I had no idea what it was so took to YouTube to find out what it was. I was sceptical as I thought exercise would make me worse as I struggle to breathe doing the simplest of tasks.

“Due to the pandemic I had to wait two years for the course to restart. It was then done virtually which was great as I work night shifts. It really boosted my confidence and I felt my health definitely improved.”

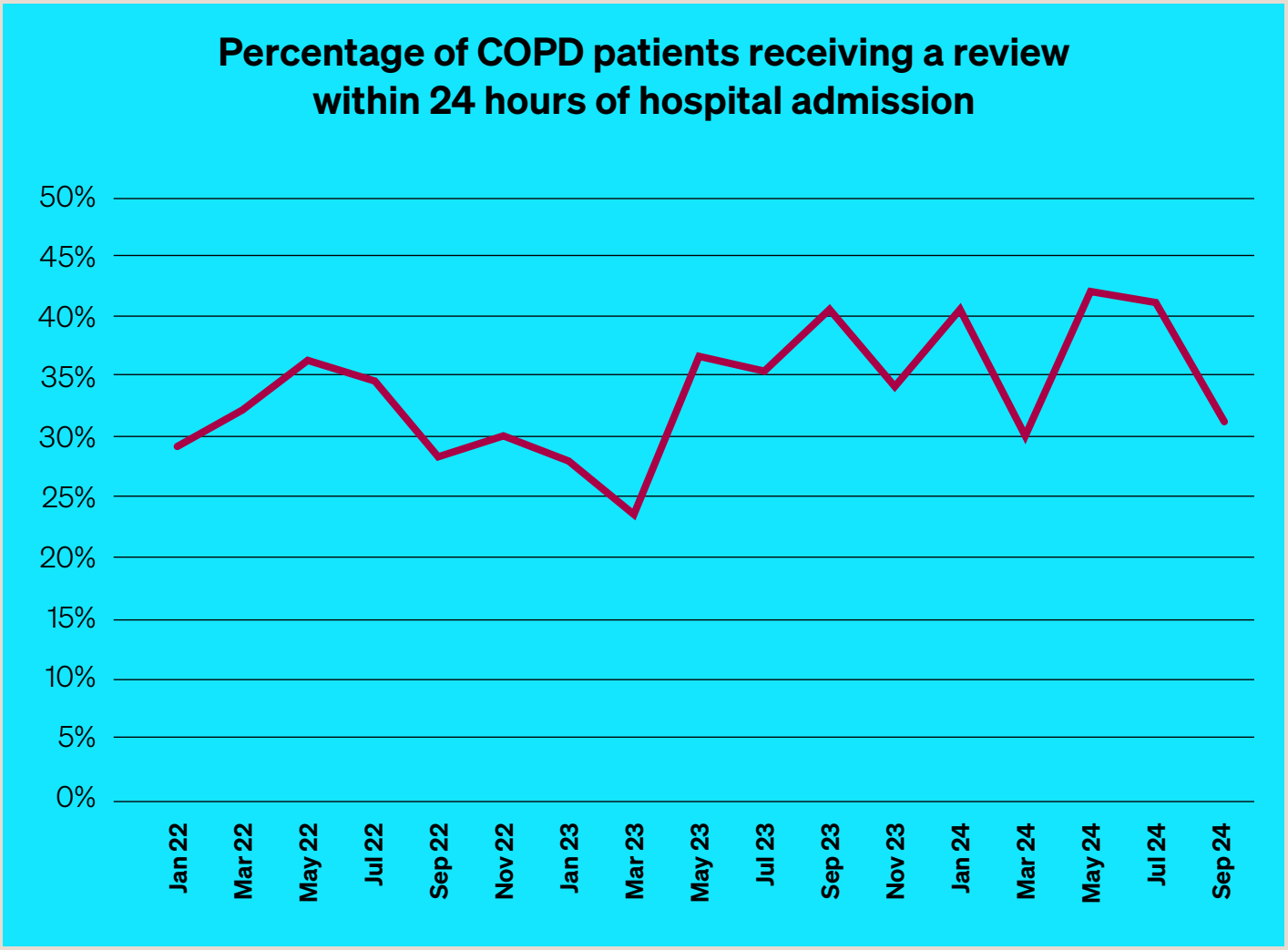
Health boards must ensure that patients who would benefit from PR can access fully staffed services without unreasonable waiting times.

Timely

When a person has to be admitted into hospital, time is an incredibly important factor. We are used to hearing shocking tales of long waits inside hospitals, leading to poor outcomes for patients and even preventable deaths.

Quality Statement attribute 21 states that **"all patients admitted to hospital with a primary respiratory illness are seen by a respiratory specialist within 24 hours."** [58]

Recent data from NRAP shows that since the publication of the quality statement, there has been virtually no improvement in this metric for patients with COPD. The total number of patients receiving a review within 24 hours is just 30.8%[59].



NRAP states that best practice would be around 60%[60]. However, in Wales, we are a long way from achieving even that metric. Without useable data produced in real time, innovation and appropriate staffing for respiratory, Welsh Government's goal of all patients being reviewed within 24 hours seems fanciful.

Winter pressures

Quality Statement attribute 23 states: **"Health boards and Trusts plan for seasonal variation in acute respiratory exacerbations and provide rapid access, community-based services, to avoid unnecessary admissions."** [61]

The winter of the publication of the quality statement saw the highest admissions for influenza and pneumonia since before the COVID-19 pandemic. Welsh Government reports that in Winter 2022/23, there were 14,603 admissions due to these respiratory infections[62].

Following this peak, in winter 2023/2024, Public Health Wales reported an unprecedented peak in the number of admissions for RSV[63].

It is clear that the publication of the quality statement has not yet had any effect on the timeliness of respiratory care in Wales. Without a concrete plan for health boards, it is unlikely this document will have any effect in the future.

Welsh Government must treat winter respiratory admissions as the crisis they are and produce clear guidance to the public, health boards and primary care on how to reduce the harm caused by cold weather. This must be coupled with cross-government working to ensure those in the poorest areas, who may struggle with increased costs at this time, are not left behind.

Welsh Government need to prioritise the diagnosis of respiratory patients.

Conclusion

As we have shown, respiratory care in Wales is facing huge challenges. In many areas, basic all-round good care is not being delivered. The quality statement does not go far enough in giving health boards clear measurable expectations and a road map of how to deliver them. The issues raised in this report show that without greater detail, respiratory care will not improve.

Health boards must go to back to basics and consider primary and secondary care holistically. *A Healthier Wales* (2018) focussed on bringing care out of hospital and into the community – however, this not yet happening. Secondary care staffing levels are falling, while primary care is not providing key services to asthma and COPD patients.

We need a strong focus on community care, which delivers excellent basic care, and which is agile enough to provide accurate diagnosis and innovative treatment. It must work alongside fully staffed PR teams to ensure those with lung conditions can live full lives.

This must come in tandem with an increase in awareness of lung conditions among the general public, encouraging them to do what they can to stay well, such as stopping smoking and taking up vaccinations.

So far, the quality statement has not achieved its purpose. However, we are confident that by following our recommendations we can radically improve lung health for the people of Wales.

We need a strong focus on community care.

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Asthma + Lung UK Cymru
The White Chapel Building
10 Whitechapel High Street
London E1 8QS

0300 222 5800

wales@asthmaandlung.org.uk

AsthmaAndLung.org.uk/Wales