Cyflwynwyd yr ymateb i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar Cefnogi pobl sydd â chyflyrau cronig

This response was submitted to the Health and Social Care Committee consultation on supporting people with chronic conditions.

CC08: Ymateb gan: | Response from: Asthma & Lung UK Cymru

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19 May 2023

To whom it may concern,

Supporting people with chronic conditions inquiry

Thank you for the opportunity to respond to the 'Supporting people with chronic conditions inquiry. Lung conditions can be both acute and chronic, but the vast majority of people with lung conditions, have a chronic condition such as asthma or COPD. We think this a very important area to look at and we are grateful to the committee and all the staff supporting it, for prioritising it.

Asthma + Lung UK Cymru

At some point in our lives, one in five of us will have a lung disease. Across the UK, millions more are at risk. Asthma + Lung UK Cymru are the only UK charity looking after the lungs of Wales, and we aim to bring the needs of people with lung conditions to the forefront of policymaking.

As we've seen with the COVID-19 crisis, acute respiratory symptoms can bring countries to a standstill and cause thousands of deaths. The recent pandemic has highlighted the need for clear and robust guidelines and support for people with a lung condition but has also shone a spotlight on the patchy provision of support and treatment for everyone who has a respiratory disease.

Through research, we can find new ways to prevent, manage (and self-manage), treat and eventually cure lung diseases.

With support, we provide for people who struggle to breathe the skills, knowledge and confidence to take control of their lives.

Together, we're campaigning for clean air, better services and investment in research and innovation.

One day, everyone will breathe clean air with healthy lungs. Only through action and commitment to change can we make that happen.

Respiratory Diseases

Respiratory disease is one of the top three killers in the UK. Every year in the UK, 115,000 people die because of lung disease. **1 in 5 people in Wales live with a lung condition** and this can vary from common conditions such as asthma, COPD and sleep apnoea to rarer conditions such as IPF.

Condition	Fact
Asthma	In Wales, 314,000 people (7.1%) are currently receiving treatment; including 59,000 children.
COPD	There are 74,000 people (2.4%) diagnosed with COPD in Wales.
Idiopathic Pulmonary Fibrosis	Approximately 2,000 people live with IPF in Wales.
Bronchiectasis	It is estimated that around 1 in every 1,000 adults in Wales have the condition.
Obstructive Sleep Apnoea	It is estimated that at least 13% of adult men, and 6% of adult women live with obstructive sleep apnoea.
Air Pollution	Around 2,000 people in Wales die early every year due to dirty air.

Lung disease in Wales cost over £500 million, making it the fourth most costly disease area.

Out of 37 nations, **Wales had the highest rate of respiratory death in Western Europe**[i] - 160.67 per 100,000 (Turkey was the highest in Europe at 162.7). Compare this to Northern Ireland where it is 139, Scotland where it is 137 and the UK average was 134. Our rates are 4 times higher than Finland at 38.4 per 100,000.

Asthma

Asthma is one of the most common chronic conditions and is very serious. It can have a devastating impact on people's lives and tragically 75 people still die every year from an asthma attack in Wales.

In our recent survey[ii] half of people (53%) with asthma don't think that their asthma is taken seriously. More than two in five (42.5%) have faced discrimination because of their asthma. This is despite 314,000 people being affected by asthma in Wales.

Two thirds (66%) of people with asthma have uncontrolled asthma symptoms that require oral steroids (which can cause devastating side effects such as bone damage and weight gain) or multiple reliever inhalers every year. Many people with asthma therefore live in constant fear of their next asthma attack. And we know that too often- people are relying on their reliever inhaler instead of optimising effective preventative treatments, which is putting them at increased risk of a life-threatening asthma attack[iii].

Uncontrolled asthma, or sometimes referred to as 'difficult' asthma, is caused by a range of factors, often underpinned by a lack of basic care and poor self-care or self-management. These factors include poor adherence to prescribed medication,

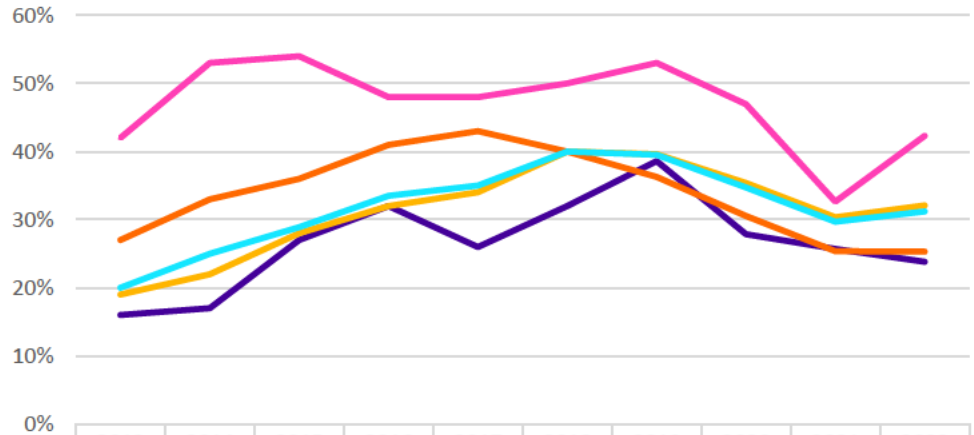
other untreated health conditions, poor mental health, smoking, lifestyle factors and even the wrong diagnosis altogether. Once again, the poorest are hit hardest. Our survey shows 73.5% from our lowest household income bracket (below £20,000 a year) have uncontrolled asthma symptoms, compared to 47.8% from the highest income bracket (above £70,000 a year).

Women are more likely to die and have uncontrolled symptoms

Our recent analysis shows that women are more than twice (2.5x) as likely to die from an asthma attack than men[iv]. Our survey also shows that women are more likely to need unscheduled healthcare and to have taken oral steroids in the last year to treat an asthma attack. Evidence suggests that sex hormones may play an important role as well as gender-based health inequalities, but this a severely under-researched area[v].

Our recent survey found the lowest levels of asthma basic care since 2017. Only 23.8% of people were receiving basic care across Wales, but this varied between health board, with the highest levels in Hywel Dda (38.2%) and the lowest in Cwm Taf Morgannwg (14%) with asthma received basic care last year. The lowest since 2015. This is equivalent to over 240,000 people with asthma not getting the fundamental basics needed to help them manage their condition.

Figure _: Basic care trends across the UK, 2013-2023



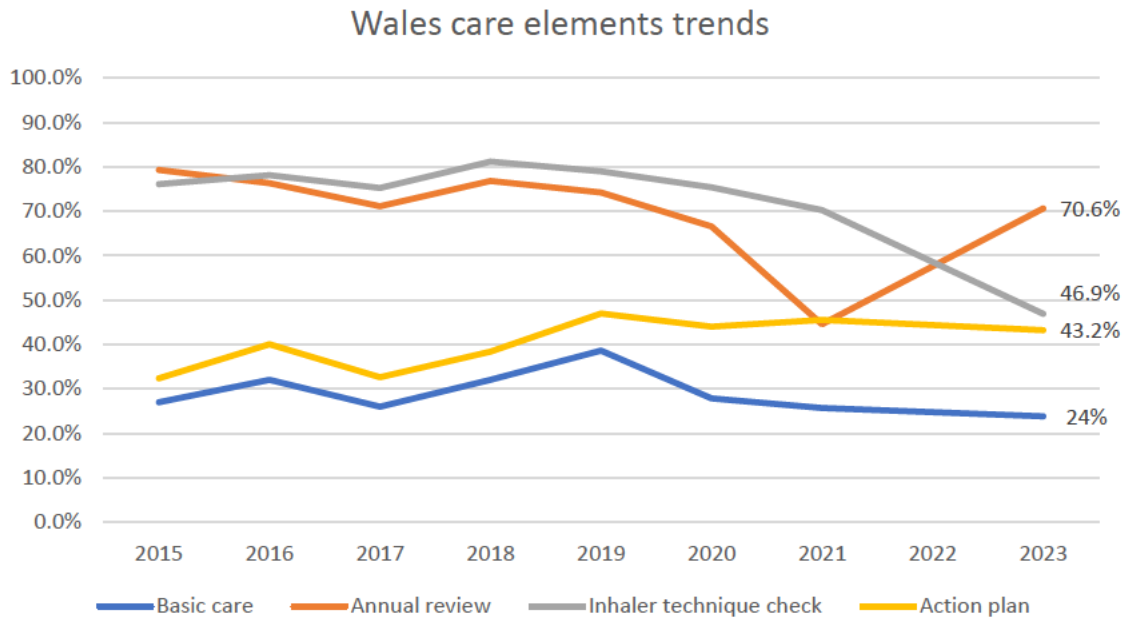
	2013	2014	2015	2016	2017	2018	2019	2020	2021	2023
Northern Ireland	42%	53%	54%	48%	48%	50%	53%	47%	33%	42%
Wales	16%	17%	27%	32%	26%	32%	39%	28%	26%	24%
England	19%	22%	28%	32%	34%	40%	40%	35%	30%	32%
Scotland	27%	33%	36%	41%	43%	40%	36%	31%	25%	25%
UK	20%	25%	29%	34%	35%	40%	40%	35%	30%	31%

Pressure on primary care

The first phase of the pandemic brought a complete stop to annual reviews for chronic conditions such as asthma. Whilst some GP practices were able to restart services via phone or video, many weren't able to deliver annual reviews and we saw the proportion of people having an annual review drop from 76.8% in 2018 to

70.6% in 2022. This key aspect of basic care being missed is likely to result in more people having poorly controlled asthma, poor inhaler technique and a lack of an up-to-date effective asthma action plan. In turn this will lead many more people being at increased risk of symptoms and asthma attacks and to higher unscheduled episodes at GP surgeries and at accident and emergency departments.

Our survey showed that only 46.9% had had their inhaler technique checked. Inhalers are produced in two categories - dry powder inhalers (DPIs) and metered dose inhalers (MDIs), but even within these categories, devices can vary and without being shown the right technique increasing the possibility of an asthma attack or other side effects. Inhaler technique training is incredibly cost-effective, ensuring medication is not wasted, reduces the risk of asthma attacks, reduces unscheduled admissions and enables people with asthma to stay well.[vi]



Our data is based on a patient survey, but the Welsh Government has also funded a primary care audit of asthma and COPD services through the National Asthma and COPD Audit Programme (NACAP)[vii] which audited patient records from 314 out of 389 practices. This audit asked a similar question on inhaler technique checks and found that as little as 25.1% had received one. There are many different types of inhalers, each with different inhaler techniques. It is crucial that health care professionals tailor inhaler devices to each individual person with asthma.

The third criteria to receiving basic care is having a written asthma action plan. Our survey found that 43.2% had one, but the NACAP audit showed only 25% of people were listed as having one on their GP record. This could mean that GPs are not recording it on their notes or potential people with asthma are using the NHS Wales asthma app or paper-based action plans, without their GPs involvement.

Diagnostic tests have also been hit hard by the pandemic. Spirometry has still not

restarted in most of primary care, despite Welsh Government instructing health boards to restart services, and fractional exhaled nitric oxide (FeNO) testing is not routinely available. The recent NACAP audit found that only 43.9% of adults and 34% of children had a record of at least one objective measurement to confirm their diagnosis. Overdiagnosis leads to unnecessary treatment such as expensive inhaled medication and repeated courses of high-dose oral corticosteroids (OCS) - both of which carry risks of side effects and significant costs to the NHS. Similarly, underdiagnosis risks daily symptoms, (potentially serious) exacerbations and long-term airway remodelling. In the 2018-20 audit, 76.3% of adults and 67.4% of children and young people had a record of at least one objective measurement, suggesting a significant number of children and adults may have an incorrect diagnosis of asthma.

Follow up for emergency or unscheduled care is also lacking
Although we have seen some improvement, our survey has shown that 50% of people who received emergency or unscheduled care did not get a follow-up within 2 working days as recommended by the National Institute of Health and Care Excellence (NICE) clinical guidelines (figure 5). In fact, 37% said they did not feel supported after receiving emergency care. This follow-up care is crucial in preventing future asthma attacks through proper assessment. It is an opportunity to deliver basic care and optimise their treatment to prevent asthma attacks.

Treating uncontrolled asthma should be simple
If we tackled uncontrolled asthma, a huge difference could be made to asthma outcomes across the UK. An approach has been developed called SIMPLES to review a person with uncontrolled asthma after a confirmed diagnosis that should be adopted across the UK. This includes:[viii]

• Support to stop smoking.
• Inhaler technique (i.e., being shown how to use their inhaler by a trained healthcare professional).
• Monitoring (assessing symptoms and monitoring peak flow).
• Pharmacotherapy (including increasing inhaled corticosteroids and addressing adherence).
• Lifestyle (advice on diet, exercise, alcohol and weight maintenance, as well addressing and treating
comorbidities).
• Education (understanding of the condition and written asthma action plan in place).
• Support (e.g., structured reviews).

Multiple opportunities are being missed to transform people's lives.
We found that in the last year most people with uncontrolled asthma didn't get the support they deserve and need:

• More than one in two (51%) weren't even asked about their asthma symptoms.
• Less than half (44%) of people who smoke were offered support to quit.
• Just 23% had their inhaler technique checked.
• Over two thirds (69%) didn't believe they had been given enough information to understand their condition or their treatments and similar numbers weren't given

the tools to help them monitor their symptoms.
• Just over a third (35%) had different treatment options discussed with them or had their inhaler changed (such as to a stronger dose preventer).
• Hardly anyone (14%) was given lifestyle advice or asked how their mental health might be impacting their asthma.

The Welsh Government must start taking asthma seriously. Over 200,000 people in Wales aren't receiving basic care and this is getting worse. We have one of the worst asthma death rates in Europe and access to life-changing treatments remains stubbornly low. A better life with asthma is entirely possible for everyone, with bold improvements to treatment, care and support.

COPD

Chronic obstructive pulmonary disease (COPD) is the name for a group of lung conditions which makes it more difficult to breathe air out of the lungs, due to a permanent narrowing of the airways and destruction of lung tissue. COPD incudes long-term (chronic) bronchitis and emphysema. In Wales, around 76,000 people live with a diagnosis of COPD and tens of thousands more are living without a diagnosis. It is the second most common lung disease in Wales, after asthma, with around 2.4% of the population living with a COPD diagnosis.

Asthma + Lung UK has gathered evidence of patient experiences of COPD care through our COPD Patient Passport, a checklist for people with COPD to ensure they are receiving the best care. Building on this and our 2021 survey, Asthma + Lung UK conducted this survey of over 6500 people with COPD between January 2022 and April 2022. Our findings in Wales are based on the experiences of 373 people with COPD. This represents a similar population share to Wales as a nation in the United Kingdom.

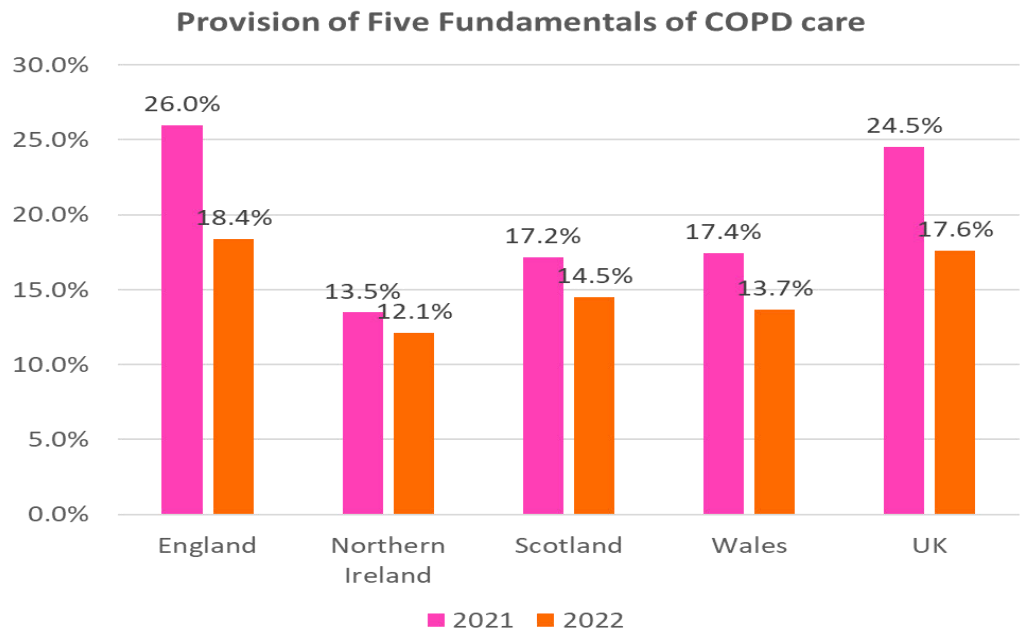
One year on from our first report in 2021, significant issues with delays to diagnosis and the quality of COPD care identified then have not been resolved and, in many cases, have deteriorated. Our survey also highlights the disproportionate impact of inequalities on people with COPD.

More people in Wales are telling us this year that they are not receiving basic COPD care

Asthma + Lung UK Cymru has found that 86.3% of respondents are not receiving the five fundamentals of COPD care, whereas our previous survey showed 82.6% did not receive the five fundamentals. This shows that more people are missing out on basic COPD care. This means that only around 1 in 7 people are being offered these basic measures of COPD care in Wales. UK wide, those that had received all five fundamentals has dropped from 24.5.% to just 17.6%, meaning less than 1 in 5 across the UK are receiving this crucial level of care.

The five fundamentals of COPD care are:
- Offer treatment and support to stop smoking
- Offer pneumococcal and influenza vaccinations
- Offer pulmonary rehabilitation if indicated
- Co-develop a personalised self-management plan

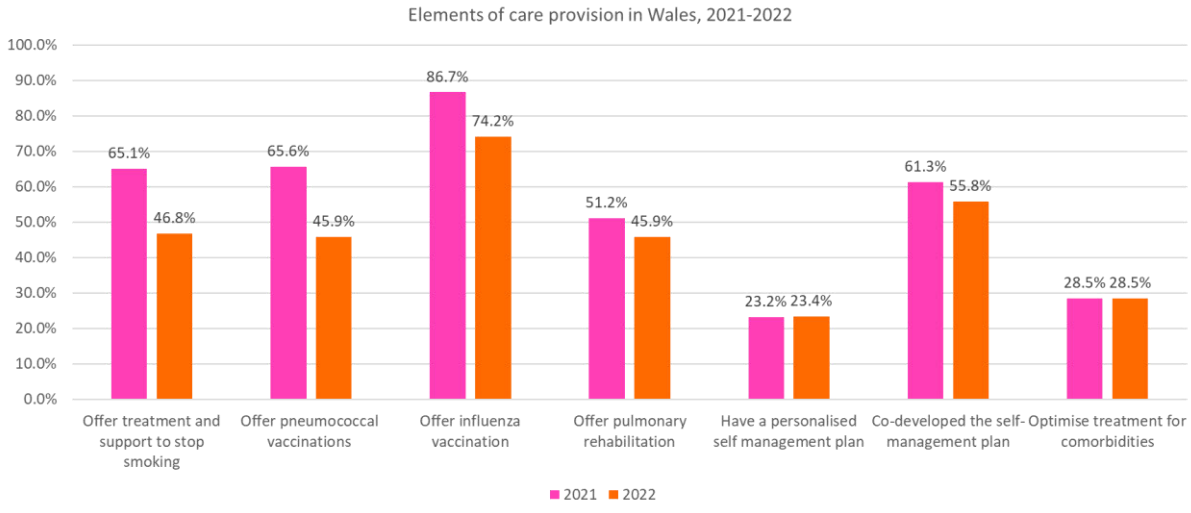
- Optimise treatment for co-morbidities.



Our results help to demonstrate the impact of COVID-19 on the care of people with lung conditions.

The survey also shows:

- Only 46.8% were offered treatment and support to stop smoking (down from 65.1% in 2021)
- 74.2% were given the influenza vaccine and only 45.9% accessed the pneumonia vaccine (down from 88.2% for influenza and down from 58.9% for pneumonia in 2021)
- 46.8% were offered pulmonary rehabilitation (down from 65.1% in 2021)
- Only 23.4% have a personalised self-management plan, with 55.8% of those plans being co-developed with a GP or primary care specialist (having a plan slightly up from 2021, while co-developing a plan down from then, 23.2% and 61.3% respectively)
- 28.5% had treatment optimised for co-morbidities (matching 28.5% in 2021)



Delays and barriers to diagnosis in Wales
Even before the COVID-19 pandemic there were already problems with diagnosis and care for people with COPD. In the past, we have estimated around 100,000 people in Wales living without a proper COPD diagnosis. Estimates across the UK range from half to two thirds of people living without a diagnosis. Our 2022 survey in Wales has found that some people are waiting as long at 10 years for a proper diagnosis from the first signs of symptoms, with 21.6% of people telling us they waited more than 4 years for a COPD diagnosis.

One of the reasons for the late diagnosis of COPD, an umbrella term for a group of lung conditions which cause breathing difficulties, including chronic bronchitis and emphysema, is a general lack of awareness about the symptoms of the disease which include breathlessness, a chesty cough and chest infections. 41.5% of people with COPD in Wales said that they were unable to recognise the symptoms of COPD. This is a significant barrier to a timely COPD diagnosis and an increase from 22.4% not knowing symptoms in our 2021 survey.

Another barrier is misdiagnosis. More than 1 in 7 said they were misdiagnosed as their doctor thought they had a chest infection or cough. The number reporting a misdiagnosis has dropped slightly from the 2021 but is still 1 in 6 people.

The need to address health inequalities - deprivation, stigma, and social isolation
The survey also highlights significant health inequalities surrounding COPD, with people from the most deprived households more likely to have flare-ups, where they struggle to breathe, than the wealthiest households.

- Poorer people with COPD have more exacerbations.
- The poorest people with COPD are being left further behind.
- Over three-quarters (75.9%) of people with COPD living in deprivation told us that air pollution impacts their health.

43.8% of people in Wales told us they feel there is a stigma attached to COPD, with one third (33.9 %) stating they have faced stigma or discrimination because of their illness. Stigma was a key theme from our 2021 survey with 46.9% feeling there is stigma attached to living with COPD, and 27.2% telling us they faced stigma and/or discrimination for having COPD.

59.9% of people told us their mental health had worsened since receiving a COPD diagnosis, with 3.8% reporting a new mental health diagnosis, 48.5% suffering anxiety and depression and 11.3% having suicidal thoughts. Yet only 20.7% who told us of the mental health impact of a diagnosis were offered mental health support from NHS Wales. Deprivation, stigma and mental health resulting from a COPD diagnosis leads to greater social isolation. This negatively impacts the employment, social life and leisure activities of people living with COPD.

The Respiratory Health Delivery Plan and the case for a new Respiratory Disease Improvement Plan

In 2014 Welsh Government published their first Respiratory Health Delivery Plan,[ix]

an ambitious document developed in the context of the Together for Health plan and designed to direct Health Boards to improve lung health, including asthma care. The document provided a 'framework for action by Local Health Boards (LHBs) and NHS Trusts' and 'set out the Welsh Government's expectation of the NHS in Wales to tackle lung diseases in adults and young people wherever they live in Wales and whatever their circumstances.'

The delivery plan would be overseen by a Respiratory Health Implementation Group (RHIG) including representation from Asthma UK and British Lung Foundation (our legacy charities)

Writing his foreword, the acting Chief Executive of NHS Wales, Simon Dean, wrote:

> 'I commit Local Health Boards and NHS Trusts, working together with their partners, to plan and deliver safe, sustainable, high quality respiratory care for their populations. I will support them in this endeavour, holding Local Health Boards to account on the outcomes they deliver for their populations and their contribution to the overall health of the people of Wales.'

Rather than focussing on conditions, the 2014 plan focussed on six themes –

- Preventing poor respiratory health.
- Detecting respiratory disease quickly.
- Delivering fast, effective treatment and care.
- Supporting people living with lung disease.
- Improving Information.
- Targeting research.

To treat asthma, health boards were required to:

- Provide patients, and carers, with relevant, appropriate and adequate information about their respiratory conditions and allergic disorders.
- Audit data on treatment steps, concordance with treatment and asthma self-management plans to support the development of improved service delivery.
- All patients attending hospital with acute asthma to have a discharge letter delivered to the GP within 24 hours, or by the next working day.

During the four years the delivery plan led to the roll out of asthma action plans across Wales, new spirometers were distributed to every GP surgery, and a Welsh Difficult Asthma Group (WeDAG) was established to coordinate the diagnosis and treatment of severe asthma.

The 2018 Respiratory Health Delivery Plan

In 2018 the second Respiratory Health Delivery Plan[x] was published with a chapter focussed on asthma. It was an ambitious 66-page document led by a National Clinical Lead, Dr Simon Barry.

The asthma chapter contained 8 actions for health boards and the Respiratory Health Implementation Group (RHIG).

Health Boards to work together to:

1. Nominate a lead physician for asthma with a dedicated secondary care asthma clinic, supported by an asthma specialist nurse.
2. Employ an asthma clinical lead within primary care responsible for implementing the recommendations from national review of asthma deaths.
3. Support the development and implementation of an up-to-date All-Wales prescribing pathway on the management of asthma, to ensure cost-effective, evidence-based prescribing.
4. Integrate asthma diagnostic guidelines into clinical practice. This will require different ways of working, such as the establishment of diagnostic hubs within primary care, with support from secondary care.
5. Ensure their asthma service is sufficiently resourced to ensure patients with severe asthma are able to access new therapies within 3 months of publication of relevant NICE guidance.

RHIG will engage with Health Boards to:

6. Support the development of an All-Wales Prescribing Pathway.
7. Support the development of the WeDAG MDT including coordinator support and database development to allow accurate record of patients discussed, recommendations and outcomes.
8. Develop an All-Wales airways database.

The 2018 delivery plan was envisaged as a three-year document, but due to the pandemic and changes in government, it remained until 2023. During this time, the NHS asthma app was launched, All Wales asthma guidelines were developed, All Wales standards and education were developed for health care professionals, and Quality Improvement projects were rolled out. RHIG received a £1 million a year to fund local pilots or national programmes during this time. Without this funding, the apps, databases and education wouldn't exist.

During the 2021 Welsh General Election we called on the next government to commit to a new Respiratory Health Delivery Plan. The existing plan had not achieved its objectives and evidence from our own annual asthma survey supported by the primary care audit, showed that services were getting worse. Nevertheless, we believed that an ambitious document with clear objectives for health boards was needed to rebuild asthma services and improve people's lives. Unfortunately, the Welsh Government chose a different approach.

Quality Statement for Respiratory Disease
Following the parliamentary review of health and social services, the Welsh Government published 'Healthier Wales: Our plan for health and social care' in 2018. This new strategy marked a shift from delivery plans to quality statements, defined as:

> 'A series of 'quality statements' which describe the outcomes and standards we would expect to see in high quality, patient focussed services will be developed for the NHS. These will set out ambitions to be delivered

consistently across Wales. They will inform national oversight of delivery through the planning framework and the performance management system.'[xi]

Starting with cancer, Welsh Government has published a series of quality statements, including one for respiratory disease in November 2022. The quality statement is fairly short at just 8 pages and contains 23 quality attributes[xii] that cut across different respiratory conditions. There are specific commitments for health boards to provide specialist teams competent in the management of asthma, to provide difficult asthma services, and to offer the NHS Wales asthma app to children and adults. RHIG will become a clinical network and the £1 million a year funding pot will be absorbed into the NHS Wales Executive.

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 Welsh Government announced a Cancer Services Improvement Plan in January 2023 but are not planning to develop improvement plans for other conditions. With 1 in 5 people affected by lung conditions and Wales having the highest level of respiratory deaths of any nation in Western Europe, we believe we need an improvement plan to implement the new quality statement.

Pulmonary rehabilitation and chronic respiratory conditions

Pulmonary rehabilitation is a programme of a minimum of 6 weeks of physical training, disease education and nutritional, psychological, social, and behavioural intervention delivered by a multi-disciplinary team.

The course will typically consist of an hour of exercise and an hour of education specifically tailored for people with a lung condition.

Depending on the particularly programme the exercise would be led by a physiotherapist or an exercise instructor with the education being led by different health care professionals depending on the topic.

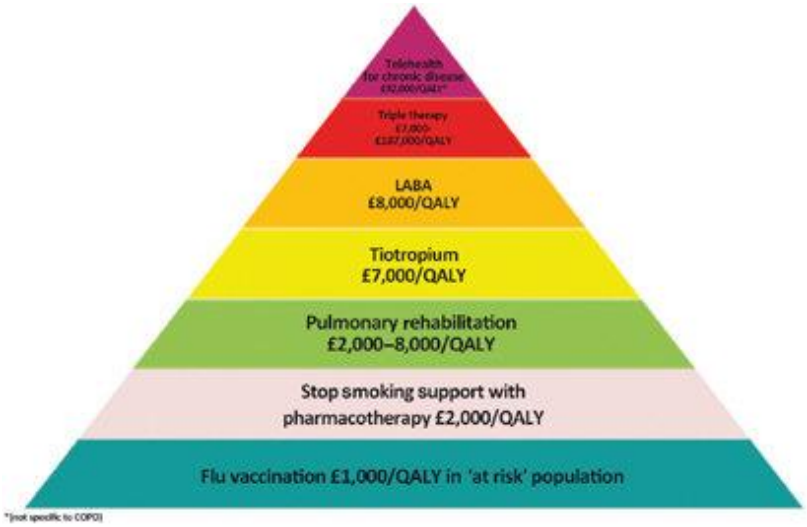
Historically pulmonary rehabilitation took place in a hospital centre although many are now delivered in community centres and sometimes leisure centres.

Pulmonary rehabilitation is free to access for patients and has been proven to be far more cost effective than inhalers, with only smoking cessation and flu vaccination having a better Quality Adjusted Life Years (QALY) cost.

COPD Value pyramid

In 2011 the NHS London developed the COPD Value Pyramid demonstrating the cost effectiveness of different medical interventions to the quality of life of people living with COPD. The Value Pyramid has since been rolled out across the UK and is recognised by the Welsh Thoracic Society as a valid tool.

The pyramid shows interventions such as Flu vaccinations, smoking cessation and pulmonary rehabilitation are more cost effective than spending on inhalers (in particular triple therapy) and telehealth.



Pulmonary rehabilitation (and the National Exercise Referral Scheme) is very cost effective in the management of COPD. Not only is the cost per QALY gained very favourable (£2,000-£8,000 per QALY), but it is also the only intervention that has been shown to reduce readmission rates at 3 months. Physical health issues also impact negatively on self-esteem, mental health, stigma, discrimination, and quality of life.

What do services look like post-COVID?

In an Asthma + Lung UK Cymru review[xiii] of PR published in November 2022, 6 out of the 7 health boards were delivering face to face rehabilitation and one health board was offering a virtual programme. Powys have continued to only offer PR virtually, which has allowed the team to access people across the county. Whilst before the geography of Powys made delivering equitable services very difficult, but virtual sessions have opened it up to everyone, who has the internet.

What has changed is that venues have been lost and services are still restricted on numbers. Hospital venues were repurposed, and community buildings were turned into vaccine centres and in some cases are still not available, whilst social distancing has capped the number of participants in many venues. This has been a particular challenge in Cardiff and Vale, where they are capped at 7 and in North East Wales where they are capped at 6-8 people. There have been attempts to reduce the length of programmes to create capacity. In North Wales the 7-week programme has been reduced to 6 weeks, whilst Cardiff and Vale have moved from 18 sessions to 13. Unless more capacity can be created with higher numbers of participants and/or more programmes it will be impossible to reduce waiting lists.

Even before COVID there were huge variations in staffing and resources. BCUHB, Cardiff and Vale, and Swansea Bay were able to rely on a wide multi-disciplinary team of health care professionals, whilst Cwm Taf and Powys tended to have services reliant on one or two health care professionals. As the appendix shows, this variation has continued and is linked to the type of service that can be offered. The Cwm Taf staffing situation has worsened with consequences explained below, whilst in Powys, staffing is part of the rationale for maintaining a virtual service.

Waiting lists
Pre-COVID waiting lists for PR varied with some health boards having large programmes with a waiting list of a few weeks and others with lists over a year. Services had used quality improvements programmes to reduce waiting list and deliver more services in community venues. The 2019 National Asthma and COPD Audit Programme (NACAP)[xiv] found that 59% of patients in Wales starting PR within 90 days of referral from primary care. However, when services were paused during the first phase of the pandemic, this had a knock-on effect on waiting lists and in autumn 2021 Asthma + Lung UK Cymru gave evidence to the Senedd Health committee that some health boards were facing 3 year waiting lists. 18 months later and this is still the case.

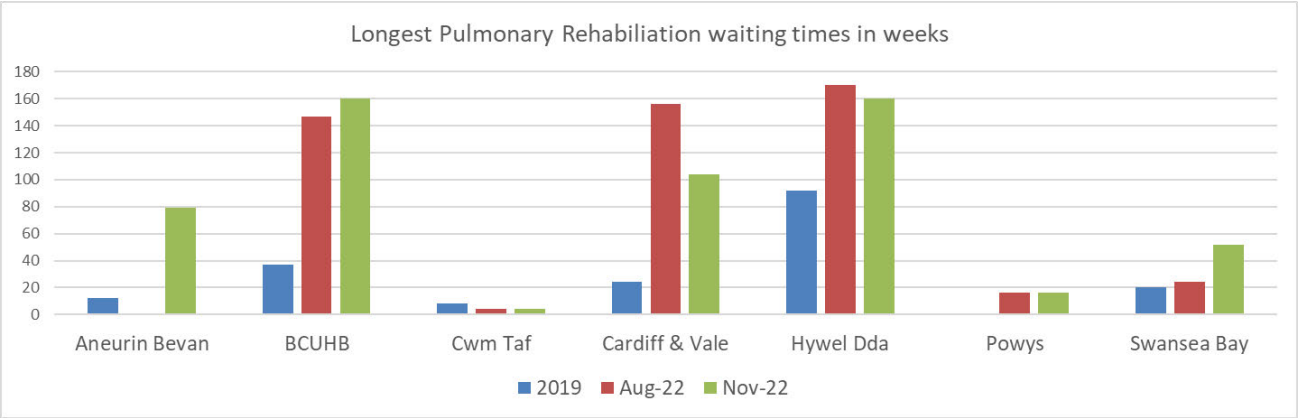
Hywel Dda, Cardiff and Vale and Betsi Cadwaladr UHBs have the highest waiting lists between 2 and 3 years. Hywel Dda estimate their waiting list is 160 weeks, whilst Cardiff and Vale are at 104 weeks. The PR teams have seen the waiting list increase each month as there are more people being referred than spaces. Due to the size of health board Betsi Cadwaladr split their PR service into 3 and the waiting lists vary from 48 in East and 50 in West, to 160 weeks in Central. Betsi Cadwaladr have lost capacity due to venues and staff, for example in Central only one out two programmes are running. Pre-COVID they had 840 spaces per year, yet now it is 630. Referrals to the service fell from 1,169 in 2019/20 to 695 in 2021/22, but now the numbers have returned to pre-pandemic levels.

Swansea Bay is the best resourced PR team in Wales. They received funding in 2015 to expand the service and sit in the primary care, communities, and therapies. Like other services, they built up a waiting list when it wasn't possible to deliver face to face services, but it is lower than other areas at 12-52 weeks depending on which programme people are booked on. The team were also tasked with setting up separate Long COVID services based on their experience of delivering pulmonary rehabilitation in the community.

Waiting list are lowest in Powys and Cwm Taf, and the teams explained that one of the key reasons is lack of referrals. In Powys the waiting list is 12-16 weeks but until recently has been a virtual service. There will be people who won't be referred because they won't be able to take part virtually, whilst there are other areas where referrals will be low for historic reasons. The virtual service appears to be working well and has positive outcomes and is more inclusive than a face-to-face service that people might struggle to drive to. It has expanded and from January 2023 it will move from Teams to Attend Anywhere to make it more accessible. They team is considering utilising private rooms in libraries to allow people who don't have computers to connect to the programme. Powys is keeping a waiting list of people unable to attend a virtual programme who would need face-to-face and are looking at what other support is available.

Whilst the waiting list in Cwm Taf (minus Bridgend) is very low (6 weeks), this is due to the service being redesignated as a respiratory exercise class, low numbers of staff, funding, and referrals. When the health board boundaries were changes and Bridgend moved into Cwm Taf Morgannwg, it was hoped that the community-based Bridgend model could be rolled out across the rest of the health board. This

sadly was not the case. Bridgend remains with Swansea Bay through an SLA, whilst the two site (Rhondda and Merthyr Tydfil) service was not invested in and only the Merthyr Tydfil site has reopened. The programme consists of a physiotherapist working alone, so it has now been re-categorised as a Respiratory Exercise Group. Rhondda Cynon Taf has some of the highest levels of COPD in Wales, yet it does not have a pulmonary rehabilitation service.



* Some data missing due to PR teams not taking part in one of the 3 audits

Referral to Treatment Time

Pulmonary Rehabilitation is not subject to the same Referral to Treatment Time (RTT) rules as many other hospitals-based treatments despite the huge amount of clinical evidence supporting it.

RTT is the time from referral by a GP to hospital for treatment and includes time spent waiting for any hospital appointments, tests, scans, or other procedures that may be needed.

The Welsh Government target is:

- 95% of patients to start treatment within 26 weeks of receipt of referral
- 100% of patients to start treatment within 36 weeks of receipt of referral

Welsh Government's waiting times are reported on the Stats Wales website and are publicly available. Health boards are transparent about their waiting lists and there is a need for health boards to meet the targets.

As there is no RTT for pulmonary rehabilitation, there is no reason for Health Boards to prioritise tackling waiting lists for this important service and the information is not publicly available.

Pulmonary Rehabilitation was over stretched and under resourced before the pandemic and was highlighted as a RHIG priority in the 2014 and 2018. The new Respiratory Quality Statement includes the following quality attribute:

> '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.'

In conclusion, the evidence base for PR is well established, it is more cost effective for COPD than anything other than smoking cessation and flu vaccinations, yet health care professionals have had to consistently justify the existence of their services, and in most cases did not have their expansion plans approved. The COVID-19 pandemic paused services and redeployed staff leading to waiting lists accelerating out of control and no way of tackling them. Unless we can increase the number of people receiving pulmonary rehabilitation then waiting lists will continue to remain high. Through a combination of increased investment, staff, larger groups and more venues, these issues can be tackled, but it is going to require local investment.

NHS Wales asthma self-management app

Building on the NHS Wales respiratory education videos, in 2020 NHS Wales launched the *Asthmahub*; *Asthmahub for Parents;* and *COPDhub* – three free-to-use self-management apps designed to help people manage their asthma treatment and care.

The purpose of the apps was to support the long-term management of patients with asthma and COPD, to ensure every patient has a personalised management plan that is clear and easily accessible in emergencies, as well as providing appropriate supplementary advice, education, and support. The apps also help healthcare professionals as a tool to promote self-management and a reliable resource to which they can signpost patients.

By May 2023 they have had over 20,000 downloads, and 99% of GP practices in Wales have patients using them. Previous data from users have shown that there is no variation in uptake geographically, nor by deprivation index of GP surgeries. The developers of the app, ICST, have found that 90% of users find the app helps them manage their condition, and that 60% of users were introduced to the apps through their healthcare professional.

How successful are the apps?

In November 2022 ICST conducted a survey sent out to 10,000 current app users receiving responses from 370 of them.[xv] They used this sample to evaluate the success of the app.

When looking at results for all users, there is an improvement in condition management after using the app and many people report a decrease in GP visits and accident and emergency admissions for their respiratory condition. 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.

Respondents were asked a similar question about the number of times they had been admitted to hospital, and on average it had fallen by 15.8%.

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%.

Feedback from users

> "It would be good if inputted data was sent to GP or asthma nurse or if they had access to the information."
>
> "It is keeping a good PF record for my consultant and evidenced changing to a new biologic."
>
> "I use the app to show my manager that I'm taking appropriate action to care for my asthma. Prior to the App I was always told if I'm not taking steroids, I'm not managing my asthma. The app has helped me educate my manager."
>
> "It's brilliant. Great information. Useful things to show and discuss with my GP."
>
> "It would be useful if GP could be more aware and accepting of the app."

The survey results are valuable when it comes to assessing how medical apps can be used to improve patient self-management of a long-term condition. Not only do users report improved measures of wellness, but also fewer GP visits and hospital admissions, reducing the burden of these conditions on the already stretched post-pandemic health system.

The benefits of using digital health solutions in healthcare seem obvious; there can be more convenience and agency for users in monitoring their own health, healthcare costs to the NHS can be drastically cut down and there can be easier and more efficient patient data collection for healthcare professionals to make informed decisions about care. The challenge lies in encouraging people to download them and continuing to use them. 20,000 downloads in a population of 3.1 million people is a good start, but we need to roll these apps out far wider to make positive change to people with asthma across Wales. High quality engaging content on the app is key, but in the long term there needs to be an interface with NHS Wales IT systems, so people feel that the data they are inputting is actually being used by their health care professional.

Ongoing evaluation and deeper understanding of patient use of the apps will be invaluable. We need to further understand how many are using it regularly, how many drop off after 6 weeks, what would help more people use it, what are clinician barriers and how can we integrate this into the new NHS Wales app. Across the UK, the lack of uptake of condition-specific apps might be explained by a desire from people not to constantly monitor their long-term condition. Insights from our work with Public Health England[xvi] have found that many people with asthma do not want to routinely acknowledge their asthma and continually monitor it. We hope to apply this research as the asthma and COPD apps develop.

Conclusion

Through this response we have attempted to share with the committee, the challenges that people with chronic respiratory conditions face. 1 in 5 people have a lung condition and most of these are chronic conditions. They should be treated in the community with individuals self-managing through written health advice, support and education from HCPs in the community, or through self-management apps. Wales has the highest level of respiratory deaths in Western Europe, the lowest levels of basic asthma care, and one of the worst levels of COPD care.

People are using inappropriate medicines, relying on reliever inhalers rather than preventer inhalers, having poor technique so not inhaling it all, and this leads to hospital admissions. This must change. We would like the Welsh Government to develop a Respiratory Disease Improvement Plan, as they have done for Cancer, and believe that they should develop Improvement Plans for other conditions to implement Quality Statements. We believe that the problems that exist in chronic respiratory conditions illustrate well the wider issues in all chronic conditions.

For further information

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