

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Effaith yr ôl-groniad o ran amseroedd aros ar bobl yng Nghymru sy'n aros am ddiagnosis neu driniaeth](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on the [impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment](#)

WT 13

Ymateb gan: | Response from: Asthma UK a Sefydliad Prydeinig yr Ysgyfaint Cymru | Asthma UK and British Lung Foundation Wales

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Thank you for the opportunity to respond to the *'Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment inquiry'* by giving verbal evidence and providing a written contribution now. 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.

### About Asthma UK and British Lung Foundation

Building on existing collaboration, in January 2020 Asthma UK and the British Lung Foundation merged to become the Asthma UK and British Lung Foundation.

At some point in our lives, one in five of us will have a lung disease. Across the UK, millions more are at risk. We are the only UK charity looking after the lungs of Wales.

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. We want to see proactive and holistic approaches to help prevent, diagnose and treat lung conditions so that we can all live better, healthier lives.

- 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.

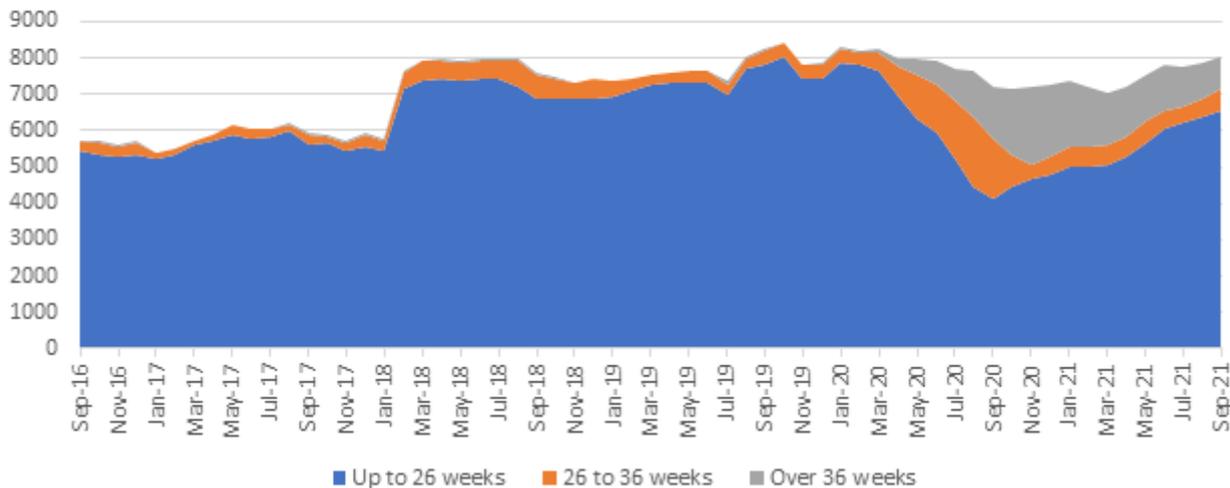
## Secondary care waiting lists

As COVID-19 is a respiratory pandemic, the number of people waiting over 26 weeks jumped dramatically as consultants and nurses were redeployed and found themselves leading secondary care COVID services rather than seeing patients with severe asthma, idiopathic pulmonary fibrosis or other lung conditions.

The current targets for referral to treatment times are 95% of patients should be waiting less than 26 weeks and no patients should wait longer than 36 weeks for treatment.

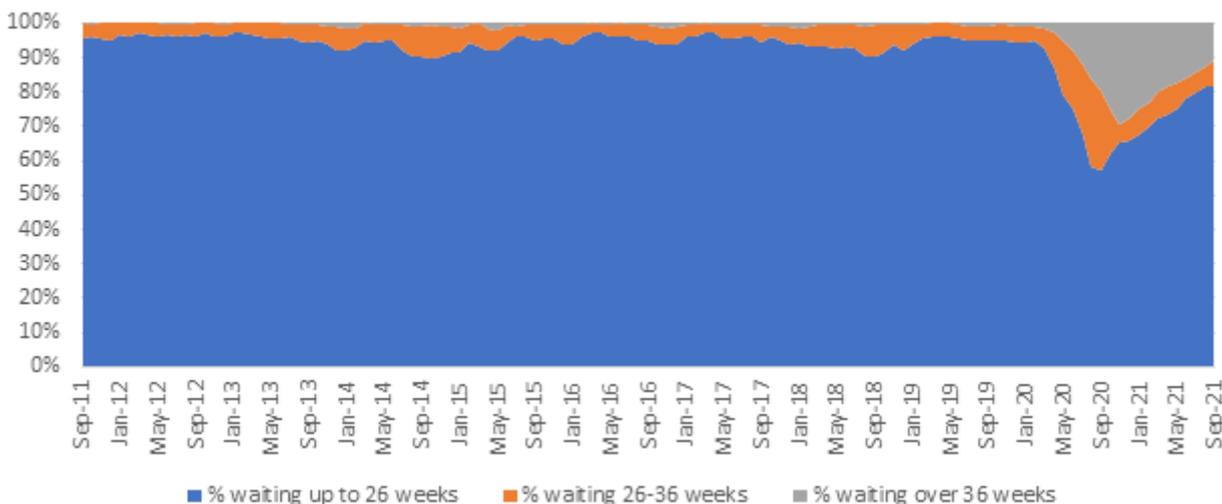
Over a 5 year period the respiratory waiting times are as follows:

Referral waiting times for respiratory medicine



The most recently data available is from September 2021 with 81.7% were waiting less than 26 weeks. This up from a low of 58.5% in August 2020. Pre-COVID, over 90% were seen within 26 weeks, and waits over 36 weeks were very rare.

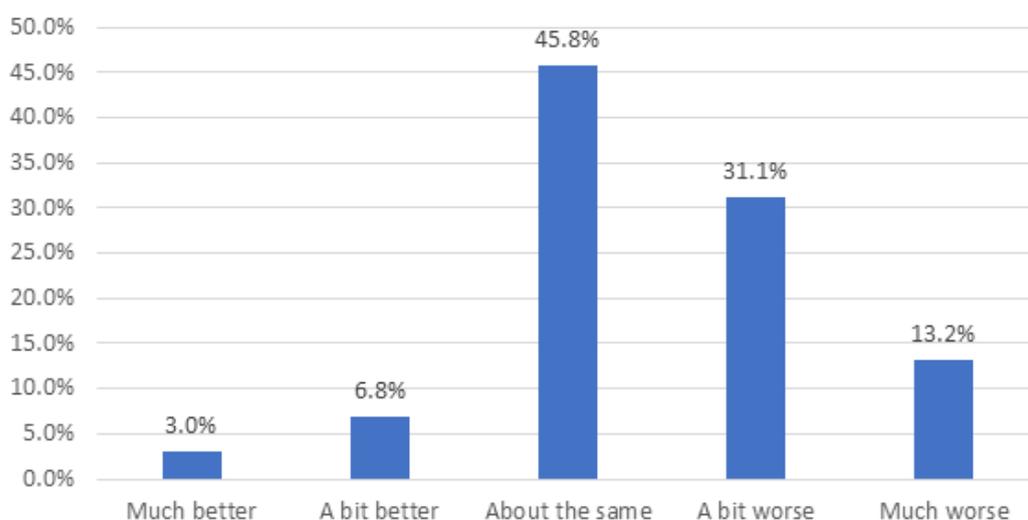
Percentage of patients waiting for respiratory care



The specific breakdown of waiting lists across different respiratory conditions across health boards is not published by the NHS so it is difficult to provide exact figures. However, in preparation for our oral evidence session, we were able to give the example of Cardiff and Vale University Health Board, where the waiting lists in December 2021 for Bronchiectasis stood at 6-8 weeks for urgent treatment and 10 weeks for routine treatment. For interstitial lung disease it was 6-8 weeks for urgent treatment and 21 weeks for routine treatment, whilst for asthma it was 6-8 weeks and 18 weeks. The health board weren't able to share information about other lung conditions or treatments.

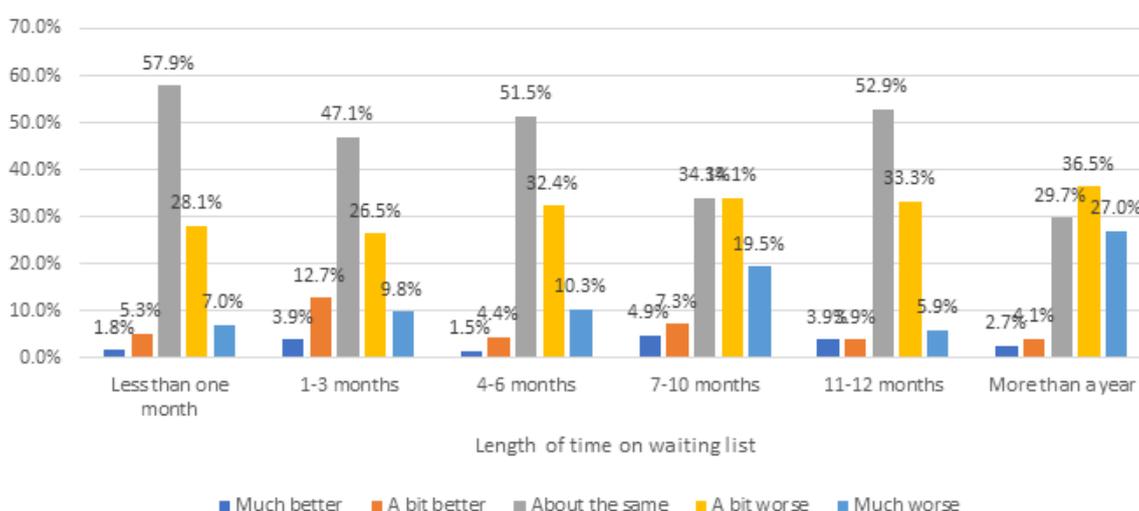
Being on a waiting list has a serious impact on people's lung conditions. In our research on healthcare last winter, 44.3% of people with a lung condition on a waiting list<sup>1</sup> told us their lung condition had deteriorated since being put on a waiting list.

How has your lung condition been since being put on the waiting list?



The longer people are on a waiting list, the worse their condition gets. For those on a waiting list for over a year, 63.5% told us their lung condition got worse. For those waiting more than 6 months, 53.6% told us that their lung condition got worse.

Time on a waiting list, and impact on lung condition



## Primary care and diagnosis

For the majority of people with lung conditions, most of their treatment and support is in primary care through GPs, nurses and pharmacists. In May 2021 we published our Annual Asthma Survey<sup>1</sup> looking at basic asthma care in Wales.

This year's survey has revealed that over 220,000 people with asthma in Wales have not had their annual review face-to-face and are missing out on life-saving basic care.

Of those who are most at risk of an asthma attack and experiencing uncontrolled symptoms such as using a reliever inhaler three times a week or more, or waking in the night feeling breathless, with a cough, tight chest or wheezing:

- Over a quarter (28%) have not had their annual asthma review
- One in five (21%) have not had their inhaler technique checked
- Nearly half (47%) do not have a written asthma action plan which includes information on what to do if your asthma is getting worse and is crucial in preventing asthma attacks

In November 2021 we published our first Annual COPD survey<sup>2</sup> focussing on the five fundamentals of basic COPD care. The report found that

### 1. COPD care - low standards and huge variations

- Across Wales, only 17% of people received the five fundamentals of COPD care as set out in NICE clinical guidelines.
- Those with a recent diagnosis were most likely to receive the lowest levels of care and there is a clear relationship between length of time since diagnosis and receiving the five fundamentals of COPD care.
- Respondents who reported receiving the basic standards of COPD care had fewer exacerbations, were better able to self-manage their condition, and better understood what to do when their symptoms worsened.

### 2. COPD diagnosis - delays and missed opportunities

- Identification of COPD is poor, with 14.6% of respondents reporting an initial misdiagnosis, 21.6% having their symptoms mistaken for a chest infection or cough, and 2.4% being sent away by their GP after raising their COPD symptoms.
- 54.6% of respondents did not feel that they had enough support and knowledge to manage their COPD post diagnosis, and only 37.9% remembered receiving written support materials to support their new diagnosis, despite NICE specifying that all patients with COPD should receive this.

### 3. What does it mean to live with COPD?

- Over 10,000 people across Wales have had their working lives cut short by COPD.
- Over half (56.8%) of respondents told us their mental health had worsened since receiving a COPD diagnosis.

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<sup>1</sup> <https://www.asthma.org.uk/support-us/campaigns/publications/survey/>

<sup>2</sup> [https://blog.blf.org.uk/blog/failing-on-the-fundamentals?\\_ga=2.109601093.1187515051.1641816772-861070808.1587709363](https://blog.blf.org.uk/blog/failing-on-the-fundamentals?_ga=2.109601093.1187515051.1641816772-861070808.1587709363)

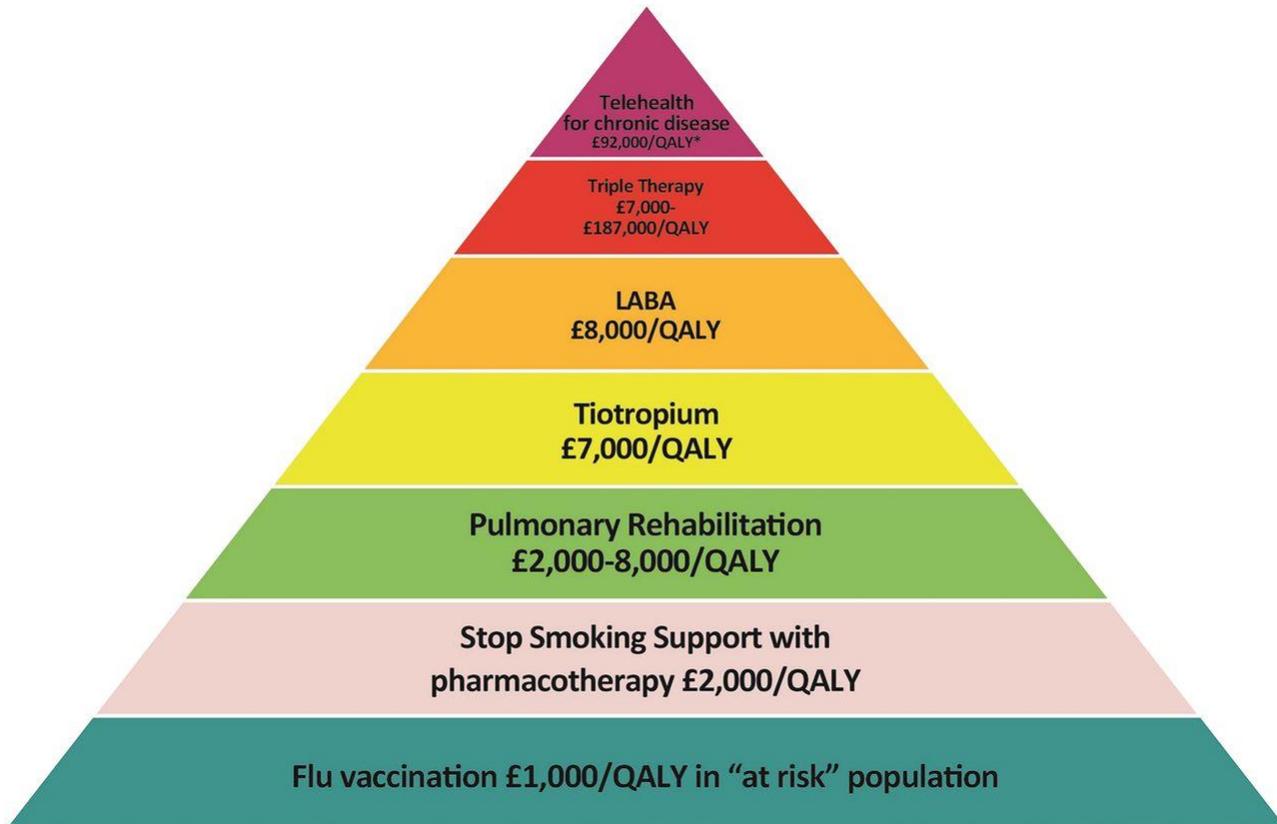
4. Perceptions of COPD - misunderstood and left behind
- COPD is misunderstood among the wider public. Nearly half (46.7%) of respondents thought that people thought badly of them because they had COPD, while 27.2% told us they had faced direct discrimination since they were diagnosed.

We would like to draw the Committee’s attention to the waiting lists for diagnosis of lung conditions in Wales. Sadly, times for diagnostic waits for spirometry (the main method for diagnosing COPD and an important tool for assessing other lung conditions) are not collected in Wales<sup>3</sup>. Overall in Wales, 23.7% are waiting over 14 weeks for some form of diagnostic service.

From speaking to respiratory health care professionals, we are aware that the waiting list for spirometry testing has increased dramatically due to COVID-19. Spirometry is a simple test used to help diagnose and monitor certain lung conditions by measuring how much air you can breathe out in one forced breath. It should be available in every practice and as part of the Respiratory Health Delivery Plan every GP practice was issued new equipment and training for their staff to ensure that people with COPD could be diagnosed properly. Pre-COVID there were no waiting lists as the test could be done in the surgery, but due to concerns about it potentially being an ‘aerosol-generating procedure’ most primary care testing has stopped, with huge delays building up for secondary care diagnostic centres.

**Pulmonary rehabilitation**

The final area we would like to draw the committee’s attention to is pulmonary rehabilitation (PR). This is a treatment programme made up of a physical exercise programme designed for people with lung conditions, and information on looking after your body and your lungs. It is designed for people diagnosed with a lung condition who are breathless, mainly people with COPD, but people with bronchiectasis and IPF can benefit as well.



<sup>3</sup> <https://statswales.gov.wales/catalogue/health-and-social-care/nhs-hospital-waiting-times/diagnostic-and-therapy-services/waitingtimes-by-weekswait-hospital>

PR is delivered by a multi-disciplinary team of trained health care professionals such as physiotherapists, nurses and occupational therapists. It is very cost effective intervention and financial modelling for COPD has shown it to be the third best intervention after flu vaccination and smoking cessation.

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 up to 6 months. The 2019 National Asthma and COPD Audit Programme<sup>4</sup> (NACAP) found that 59% of patients in Wales starting PR within 90 days of referral from primary care.

COVID-19 has sadly had a detrimental effect on the PR programme. For much of 2020 and 2021, group based pulmonary rehabilitation was forced to stop due to the risk of spreading the virus. Hospital gyms were taken over as offices, leisure centres were closed or became vaccine centres and staff were redeployed. When staff returned to their roles they piloted virtual PR and one-to-one sessions, but this covered a small percentage of those waiting for this important service. Waiting lists increased and the people waiting got more deconditioned and more affected by their condition.

In autumn 2021 Betsi Cadwaladr PR team estimated their waiting list for PR was approximated two years, whilst Hywel Dda PR teams estimated their lists might be as high as three years. Whilst PR programmes can now take place, staff have had to adjust their programmes and either find bigger venues or have smaller classes to ensure people can exercise safely and maintain social distance.

This pattern of large waiting lists is repeated across most PR teams but unusually not all, and we were keen to raise this with the committee. The PR teams in Powys and Cwm Taf told us that they had very small waiting lists due to GPs not referring to them. It appears in both health boards that as GPs knew the services weren't operating and their patients couldn't get the necessary benefit from them, that they have not been referring throughout the pandemic. This is an unusual situation but it demonstrates that waiting lists are not always what they seem. People with lung conditions live in these health boards and need PR (in fact Cwm Taf has some of highest prevalence clusters for COPD in Wales) but yet GPs have not referred people into the service.

## Concluding Remarks

Thank you again for the opportunity to provide oral and written evidence to the committee. We look forward to reading your report.

Yours sincerely,



**Joseph Carter**  
**Head of Devolved Nations**  
**Asthma UK & British Lung Foundation Wales.**

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<sup>4</sup> <https://nacap.org.uk/nacap/welcome.nsf/reportsPR.html>