

Cross-Party Group on Lung Health

Grŵp Trawsbleidiol ar Iechyd yr Ysgyfaint

Minutes from 22 November 2022

Attendees

MSs

John Griffiths MS (and supported by Shah Shumon)
Mike Hedges MS (represented by Ryland Doyle)
Ataf Hussain MS
Rhun ap Iorwerth MS (represented by Rhys Hughes)
Jayne Bryant MS (represented by Libby Bradbury)

Non MSs

Joseph Carter - Asthma + Lung UK Cymru (Secretariat)
Andrew Cumella
Anthony Davies
Anna Francis
Chris Davies
Chrissie Gallimore
Dave Edwards
Jennie Stone
Joanne Allen
Josephine Cock
Jonathan Morgan
Julie Mayes
Kimberley Lewis
Neil Harris
Nicola Perry-Gower
Pam Lloyd
Rebecca
Sarah Cadell
Simon Barry
Stephanie Morgan
Stephanie Woodland
Tracy Cross
Valerie Ann Tweedie
Val Maidment
Verdun

Apologies

David Rees MS
Vikki Howells MS
Jane Dodds MS

Natasha Asghar MS
Hefin David MS
Luke Fletcher MS
Tom Giffard MS
Sian Gwenllian MS
Altaf Hussein MS
Mark Isherwood MS
Sarah Murphy MS
Rhys ab Owen MS
Rhianon Passmore MS
Jack Sargeant MS
Cefin Campbell MS
Rhun ap Iorwerth MS
Hannah Blythyn MS
Mick Antoniw MS
Carolyn Thomas MS
Samuel Kurtz MS
Llyr Gruffydd MS
Delyth Jewell MS

1. John Griffiths MS - Welcome and introductions

John Griffiths MS started the meeting and thanked everyone for attending. asked if any MSs or support staff wanted to introduce themselves. **Altaf Hussain MS** introduced himself.

John Griffiths MS explained that there were three presenters today, **Andrew Cumella, Julie Mayes** and **Dr Simon Barry**.

He encouraged people to put any questions they had in the chat.

2. John Griffiths MS - Minutes of the last meeting

The minutes were proposed by **David Rees MS** and seconded by **John Griffiths MS**.

3. Joseph Carter - Matters arising

The following actions had been agreed at the previous meeting

- **Action - Joseph Carter** to submit AGM paperwork to the Table Office
 - Submitted
- **Action - Joseph Carter** to draft letter for **John Griffiths MS** to send to the Minister
 - Completed

4. Andrew Cumella, Asthma + Lung UK Cymru - Launch of the Annual COPD report

Andrew Cumella presented the findings from the 2022 COPD report - 'Delayed diagnosis and unequal care'. The report was based on the responses of over 6,000 people including 373 in Wales.

The report focussed on access to 'basic' COPD care, which is measured by the proportion of people receiving the 5 fundamentals as defined by NICE and being offered the following:

- 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.

The report found that across the UK fewer people were receiving basic care than in 2021, falling from 24.5% to 17.6%. In Wales, the figure had fallen from 17.4% to 13.7%.

Across health boards the survey showed quite a wide variation in results with Aneurin Bevan UHB having the highest percentage of people accessing basic care (19%), with Hywel Dda UHB the worst at just 7.9%.

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 as 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.

Andrew ended by setting out the following asks of Asthma + Lung UK Cymru:

- Funded implementation of the new Welsh Respiratory Quality Statement
- A public awareness campaign to raise awareness of the symptoms of COPD
- Urgently improve the provision of spirometry testing in primary care for the diagnosis of COPD and other respiratory conditions.
- Better targeting for lung health checks for people at risk of COPD
- Improve availability of pulmonary rehabilitation and smoking cessation services

John Griffiths MS thanked **Andrew** for his presentation and invited any questions or observations.

Dr Simon Barry talked about the challenges of getting spirometry carried out in primary care. He has proposed a mixed economy to NHS Wales where secondary care hubs will take some of the spirometry, but primary care needs to be involved as well. Whilst he accepted **Andrew's** point about a significant number of people in the community have COPD but haven't been diagnosed yet, he pointed out that around 20,000 people on the COPD register don't have COPD.

He also commented in the state of smoking cessation services in Wales. He estimated that only 2.5% of smokers are accessing smoking cessation services and there are huge inequalities. He worries that the services we have developed are not working for people from more deprived communities.

Kimberley Lewis echoed **Simon's** concerns about misdiagnosis. She has given 50 people spirometry in the last week and found that most didn't have obstructive lung function. She worries they are seeing people with signs of possible heart failure.

5. Julie Mayes - the patient perspective

Julie Mayes from South Powys gave her personal perspective of someone living with COPD. She was diagnosed about 20 years ago. She is a former smoker, and this led to her quitting. She has asthma as well and says that her GP seems more focused on the asthma. She talked about how COPD affects her life, particularly in the winter months as she can't breathe properly when it is cold. She said that everyday tasks like housework become really difficult. Sometimes she feels embarrassed when people visit if her house isn't tidy, because she is too breathless to clean up.

About 3 years she had a really bad attack of the flu. She talked about the benefits of the flu and pneumococcal vaccines.

She gets very breathless walking up hills and finds she can't talk.

She feels that there is support in primary care for people with asthma, but not COPD. With rehabilitation, she feels there is a lot of focus on cardiac

rehabilitation, but not pulmonary rehabilitation. She would really benefit from a local group being established in South Powys if there was one. At this point, **Julie** had a power cut and dropped out of the call. When she returned **Joanne Allen** from Powys Health Board offered to get in touch to discuss the specific local issues she faced.

6. Dr Simon Barry - National respiratory priorities

Dr Simon Barry shared some evaluation results of the asthma and COPD NHS Wales apps.

RHIG work with ICST to develop innovative interventions including the asthma and COPD (as well as post-COVID) apps.

Through the apps people can be offered education and notified about vaccination, when they need to record symptoms and medications etc.

What progress is being made with the apps.

- 20,000 downloads for asthma and COPD
- Coverage across 99% of practices
- No geographic variety in coverage - North, South, East and West
- No variation in deprivation index based on postcode
- 90% patients using the apps say it helps them manage their condition

People using the apps were asked the following questions:

- How long have you been using the app for?
- How often are you using the app?
- Prior to downloading the app, how well was your condition managed?
- Since downloading the app, how well is your condition being managed?
- How often are you having to visit the GP as a result of your respiratory condition now, compared to before you downloaded the app?
- Compared to before you had the app, how do you feel the app has impacted the number of A&E visits you have needed to have because of your respiratory condition?
- Do you have anything else regarding the apps that you would like to add?

For patients who regularly use the respiratory apps for more than 6 months:

- 36% of users reduce their visits to the GP practice
- 19% reducing their admissions to Accident and Emergency

For patients whose control score was less than 5 prior to downloading the app, and use it more than once a month:

- 44.3% of users reduce their visits to the GP practice
- 33.3% reducing their admissions to Accident and Emergency

John Griffiths MS thanked **Simon** and **Julie** for their presentations and asked if anyone wanted to ask a question.

Joseph Carter asked **Julie** whether she had in-person or virtual reviews with her GP or practice nurse. He encouraged her to try the asthma and COPD apps.

Julie said she has regular asthma reviews with her practice nurse. She said it is difficult to see a GP and she would explore the apps.

<https://healthhub.wales/>

Valerie Ann Tweedie also lives in South Powys and she felt she had little support from her GP practice. They will prescribe her different inhalers but won't see her and talk about her symptoms and condition.

Joanne Allen offered to speak to **Valerie** as well.

Action: Joseph Carter to share details of **Julie Mayes** and **Valerie Ann Tweedie** with **Joanne Allen**.

Action: Joseph will draft a letter to **Eluned Morgan MS** summarising the results of the COPD survey and the evaluation results from the apps.

Action: Joseph will share the briefing from **Dr Simon Barry** with all MS.

7. **Joseph Carter** - Next meeting and the work ahead

John Griffiths MS asked **Joseph Carter** to talk about the future meetings. **Joseph** thanked everyone for their contributions and for making the time to come and confirmed that the next meeting would be on 14 February 2023 where we will focus on the Respiratory Quality Statement.

8. **John Griffiths MS** - Any other business

John Griffiths MS asked if anyone had any other business. They didn't, so he thanked everyone for attending and brought the meeting to a close.