

Cross-Party Group on Lung Health

Grŵp Trawsbleidiol ar Iechyd yr Ysgyfaint

Minutes from 16 November 2021

Attendees

MSs

John Griffiths MS (Chair)

Heledd Fychan MS

Jane Dodds MS

David Rees MS

Rhun ap Iorwerth MS

Huw Irranca-Davies MS (represented by Harry Davies)

Heledd Roberts (supporting Rhun ap Iorwerth MS)

Charlotte Knight (representing Jayne Bryant MS)

Andrew Betteridge (supporting John Griffiths MS)

Non MSs

Joseph Carter - Asthma UK and British Lung Foundation Wales

Andrew Cumella - Asthma UK and British Lung Foundation Wales

Stephanie Woodland - Asthma UK and British Lung Foundation Wales

Alice Spencer

Beccy

Brian Forbes

Carys Morgan-Jones

Ceri Lane

Ceri Gambold

Chrissie Gallimore

Delyth Smith

Derek Cummings

Gloria Jenkins

Jan Douglas

Jane Mullins

Jeannie Wyatt-Williams

Jo Allen

John Morgan

Jonathan Morgan

Kimberley Lewis

Laura Edwards

Nicola Perry-Gower

Ruth Evans

Ryland Doyle

Stephanie Phillips Morgan

Tom Lines

Apologies

Natasha Asghar MS
Alun Davies MS
Paul Davies MS
Luke Fletcher MS
Llŷr Gruffydd MS
Janet Finch Saunders MS
Peter Fox MS
Russell George MS
Mike Hedges MS
Altaf Hussein MS
Mark Isherwood MS
Samuel Kurtz MS
Sarah Murphy MS
Rhys ab Owen MS
Peredur Owen Griffiths MS
Jack Sargeant MS
Carolyn Thomas MS
Buffy Williams MS
Sioned Williams MS

1. John Griffiths MS - Welcome and introductions

John Griffiths started the meeting and thanked everyone for attending. He asked Heledd Fychan MS, Jane Dodds MS, David Rees MS and Rhun ap Iorwerth MS to introduce themselves.

He explained that there were two presenters today, Andrew Cumella and Brian Forbes, and he encouraged people to put any questions they had in the chat.

2. John Griffiths MS - Minutes of the last meeting

The minutes were approved after being proposed by Jane Dodds MS and seconded by John Griffiths MS as an accurate record of what was discussed.

3. Joseph Carter - Matters arising

The following actions had been agreed at the previous meeting

- **Joseph Carter** to complete the paperwork to register the Cross-Party Group on Lung Health
 - Completed

- **John Griffiths MS** to sign the form and submit to the Senedd Commission
 - Completed
- **John Griffiths MS** and **Joseph Carter** to agreed dates for future meetings
 - Completed and covered later in the meeting
- **Joseph Carter** to write to **Eluned Morgan MS**
 - Completed. **Joseph Carter** explained that the Minister had responded but was not willing to meet with the CPG at this time.
 - **Action** - **Joseph Carter** to share the response with the minutes

4. **Andrew Cumella, Asthma UK and British Lung Foundation Wales** - Launch of the first Annual COPD report

John Griffiths MS introduced **Andrew Cumella**, Senior Analyst at Asthma UK and British Lung Foundation and thanked him for attending. Andrew's slides will be circulated with the minutes but some of the key highlights are captured below.

Asthma UK and British Lung Foundation conducted this UK survey of over 8,000 people with COPD between December 2020 and May 2021. Even before the pandemic, it is clear from the responses that many people with COPD had experienced unacceptable delays before a diagnosis was made. During this period, the impact of COVID-19 considerably worsened people's daily lives, their chances of being diagnosed, and the level of care they received. Recent health board figures found that diagnosis rates - which were already far too low - plummeted even further due to fears around spirometry being an aerosol generating procedure.

As of November 2021, diagnostic tests such as spirometry have not yet properly resumed, making it likely that thousands of people may have gone undiagnosed in 2021. While rates of cancer diagnosis are already up to pre-pandemic levels, there is no dedicated plan to address the huge backlog in respiratory care. The charity argue that we need a new Lung Health Quality Statement to address this issue urgently.

AUK-BLF found that across Wales, only 17% of people with COPD are receiving what NICE clinical guidance defines as the five fundamentals of COPD care (a basic level of care comprising elements such as provision of a self-management plan, vaccinations against flu and pneumonia, referral to smoking cessation services, pulmonary rehabilitation and managing other co-existing medical problems).

England is the nation with most people receiving basic care, but this is still low at 26%. Receipt of these five fundamentals was more likely when more time had passed since the initial diagnosis. This may be because people with COPD have to learn how to navigate the NHS to get the care that they need, and this is time during which their health may deteriorate considerably. Alternatively, it may be that healthcare professionals do not prioritise treatment until a patient has deteriorated. Neither scenario is acceptable.

Headline survey findings

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.

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.

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.

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.

The full report into this survey can be found here: <https://www.blf.org.uk/copd-report>

Recommendations

Andrew concluded by setting out the recommendations of the report for Welsh Government:

- Invest in respiratory services and develop a new Lung Health Respiratory Strategy. While respiratory conditions are supposedly a clinical priority, this does not seem to be the case in practice, and we need to see ambitious targets for improving COPD prevention, diagnosis and care. The Respiratory Health Delivery Plan has concluded, so we would like to see this replaced with a new Lung Health Quality Statement, continuation of the clinical lead and coordinator roles, and a budget to invest in innovative projects to lead quality improvement.
- Urgently restart of spirometry testing in primary care for the diagnosis of COPD and other respiratory conditions. Pre-COVID the Welsh Government invested over £2 million rolling out spirometry training to primary care and

supply equipment, but even with this support the 2020 NACAP Primary Care audit for Wales showed that only 11.5% of people were receiving post-bronchodilator spirometry.

- A nationwide programme of lung screening, including spirometry, to the over-35 age group who smoke, delivered by accredited staff within primary and secondary care. If this can not be delivered in primary care, then health boards should be establishing diagnostic hubs.
- Support public awareness campaigns to improve understanding of lung conditions and when to seek medical advice for a long-term cough or breathlessness. This could be based upon the Taskforce for Lung Health's "Take a Breath" campaign, which aimed to connect people with their lungs and raise awareness of good lung health.
- Work with GPC Wales to ensure all five NICE recommended fundamentals of care are being implemented. The Five Fundamentals could be delivered if GPs and practice nurses had additional time to spend with patients and access to appropriate training. Through the Respiratory Health Delivery Plan, a wide range of online training and support in the management of COPD was developed by the Institute of Clinical Science and Technology (ICST), but health care professionals need to access it.
- Direct health boards to restart any pulmonary rehabilitation services that are yet still yet to resume. Where appropriate, face-to-face PR programmes should reopen in the community, but there are huge waiting lists, classes need to be smaller due to social distancing requirements, and some venues are no longer available.
- Everyone with COPD and other lung conditions should have the right to pulmonary rehabilitation, but services are restricted to people with moderate to severe COPD (MRC grade 3 and above), meaning that many people are considered too well to be referred. We would like to see Health Boards invest in pulmonary rehabilitation and design systems to enable self-referral.
- Continue the roll out of the new NHS Wales asthma and COPD apps. The new bilingual NHS Wales apps offer the potential of people with COPD (and asthma) to have a greater role in managing their condition, track their symptoms, access information and support, and reduce the risk of an exacerbation.
- Ensure health board implement training in Very Brief Advice for Smoking Cessation across primary care and smoking cessation should be made a core part of undergraduate and postgraduate medical training, with a focus on delivery for those with respiratory conditions as well as incorporation into guidelines for the management of other long-term conditions. This would ensure that smokers who want to quit know that help is available. Public Health Wales should monitor training levels and collect data on VBA use.

- Local health services should also ensure hospitals are delivering the ‘Ottawa Model’ for smoking cessation to support people admitted to quit.
- Deliver a new smoking and tobacco strategy with a target for a smoke-free nation by 2030 (5% or less smoking population); a ban on public smoking in high streets across Wales; and a review of the minimum legal age to purchase tobacco products in Wales.
- A review into the compliance and enforcement of current tobacco advertising and prohibiting laws, to seek tougher financial penalties for companies in breach of advertising laws around tobacco products. This is to reduce the impact of selling tobacco products in our most deprived communities.

John Griffiths MS thanked **Andrew Cumella** for his presentation and invited questions.

Jane Dodds MS asked about the links between poverty and COPD. **Andrew Cumella** explained that the report hadn’t really featured poverty issues as the questions hadn’t quite worked. COPD is more prevalent in areas with high deprivation, but AUK-BLF wasn’t able to show whether basic care was any better or worse in areas with higher levels of poverty.

John Griffiths MS asked what AUK-BLF would like the CPG to do with this information. **Joseph Carter** suggested a letter to the Minister, which the chair agreed.

There were further questions in the meeting chat. **Andrew Cumella** was asked about the link between COPD and mental health, which he explained.

Another contributor suggested that as the data collection took place during COVID restrictions that there would have been more isolation because of this.

The issue of spirometry not taking place in primary care was raised. Diagnosis didn’t really feature in the report, but is a major problem with people not getting diagnosed in primary care due to fears of spirometry being an aerosol generating procedure.

Another contributor responded saying that in Powys, they have taken a pragmatic approach and restarted spirometry as a service with additional cautions (FRSM, gloves, aprons, open windows/good ventilation, staff double vaccinated) . More information about the issue can be found at:

<https://thorax.bmj.com/content/early/2021/11/02/thoraxjnl-2021-217671>

Action - Joseph Carter to draft letter for John Griffiths MS to send to the Minister

5. **Brian Forbes, AstraZeneca** - Putting a spotlight on Asthma and COPD outcomes in Wales

John Griffiths MS introduced **Brian Forbes**, Government Affairs Lead (Devolved Nations) for AstraZeneca UK and thanked him for attending. Brian's slides will be circulated with the minutes but some of the key highlights are captured below.

Respiratory diseases cause 1 in 7 deaths in Wales, asthma and COPD caused almost 10,000 deaths (2013-17).

314,000 (1 in 10) people are currently receiving treatment for asthma.

Over 70,000 people are currently receiving treatment for COPD.

The total cost of inpatient admission in Wales in 2013/14 for COPD and asthma was £250 million.

Across the UK, SABA inhaler overuse causes 250,000 tonnes of CO₂ equivalent annually.

For asthma the report focuses on the following areas:

1. Ensuring accurate diagnosis of asthma and severe asthma
2. Providing basic care to people living with asthma
3. Addressing SABA ('blue' / 'reliever') inhaler overuse - patient outcome and environmental considerations
4. Reducing over-reliance on oral corticosteroids
5. Improving access to specialist severe asthma care

Making three key recommendations:

1. Support more people with asthma to gain an accurate and timely diagnosis
2. Help people with asthma to effectively manage their condition
3. Improve care and treatment for people living with difficult or severe asthma

For COPD the report focuses on the following areas:

1. Preventing people from developing COPD
2. Managing COPD exacerbations and associated mortality burden

Making four key recommendations:

1. Improve measures to prevent people from getting COPD
2. Improve identification of 'at risk' undiagnosed patients in primary care
3. Support patients to manage their condition and reduce the risk of exacerbation
4. Work with patients and health system stakeholders to reduce the risk of exacerbation

The report calls on Welsh Government to:

1. Ensure asthma and COPD remain a Government priority
2. Refresh the Respiratory Health Delivery Plan
3. Maximise opportunities of Prudent Healthcare and Value-based Healthcare

John Griffiths MS thanked **Brian Forbes** for the presentation and invited MSs to ask questions.

Jane Dodds MS thanked **Brian Forbes** and asked whether there were specific asks that MSs could be raising with their health boards. Brian said that there were different issues in each health board and this was something he could pick up outside the meeting.

John Griffiths MS asked why Wales has the highest asthma prevalence in Europe. **Brian Forbes** and **Andrew Cumella** admitted they didn't know, suggested that this question has not been heavily researched. It is difficult to know how much of it is due to more asthma versus better diagnosing and coding.

6. **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 two meetings would be on 08 February and 10 May, and that the themes would be pulmonary rehabilitation in February and asthma in May.

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

John Griffiths MS asked if anyone had any other business. They didn't, so he reminded MSs to sign the World COPD day Statement of Opinion. He then thanked everyone for attending and brought the meeting to a close.

Action: All MSs are encouraged to sign the Statement of Opinion