

Cross-Party Group on Lung Health

Grŵp Trawsbleidiol ar Iechyd yr Ysgyfaint

Minutes from 08 February 2022

Attendees

MSs

John Griffiths MS (Chair)

Huw Irranca-Davies

Darren Millar MS

Vikki Howells MS (represented by Robin Lewis)

Jane Dodds MS (represented by Rhys Taylor)

Mike Hedges MS (represented by Ryland Doyle)

Carolyn Thomas MS (represented by Dan Rose)

Rhun ap Iorwerth MS (represented by Heledd Roberts)

Altaf Hussain MS (represented by Alex Hughes-Howells)

Andrew Betteridge and Naomi White (supporting John Griffiths MS)

Non MSs

Joseph Carter - Asthma UK and British Lung Foundation Wales

Stephanie Woodland - Asthma UK and British Lung Foundation Wales

Nicola Perry-Gower

Ruth Evans

Simon Barry

Tom Lines

Tracy Cross

Verdun Moore

Alice Spencer

Sadie Beard

Hannah Bray

Caroline Evered

Ceri Lane

Chrissie Gallimore

Gloria Jenkins

Derek Cummings

Emma Jenkins

Brian Forbes

Jeannie Wyatt-Williams

Jem Patel

Jennie Stone (patient panel)

Joanne Allen

John

John Morgan

Kathryn Singh

Keir Lewis
Lauren Edwards
Lewis
Jonathan Morgan
Neil Harris
Jane Owen
Pam Lloyd
Rebekah Mills-Bennet
Sarah Cadell
Stephanie Philip Morgan
Tom Lines
Dan Rose
Val Maidment
Melanie Nicholas

Apologies

Natasha Asghar MS
Hefin David MS
Alun Davies MS
Paul Davies MS
Luke Fletcher MS
Heledd Fychan MS
Tom Giffard MS
Llŷr Gruffydd MS
Sian Gwenllian MS
Altaf Hussein MS
Mark Isherwood MS
Delyth Jewell MS
Samuel Kurtz MS
Jack Sargeant MS
Ken Skates MS
Buffy Williams MS

1. John Griffiths MS - Welcome and introductions

John Griffiths started the meeting and thanked everyone for attending. He asked if any MSs or support staff wanted to introduce themselves. At that point **John** was the only MS present, but the staff introduced themselves. During the first presentation **Darren Millar MS** and **Huw Irranca-Davies MS** joined the meeting.

He explained that there were two presenters today, **Nicola Perry-Gower** and **Dr Simon Barry**, alongside **Ruth Evans**, **Verdun Moore**, and **Tracy Cross**, who will be sharing their experience of rehabilitation.

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.

3. Joseph Carter - Matters arising

The following actions had been agreed at the previous meeting

- **Joseph Carter** to draft letter for John Griffiths MS to send to the Minister
 - Completed
- **All MSs** to sign the statement of opinion
 - Complete - 22 MSs signed the statement of opinion including almost all the members of CPG

4. Nicola Perry-Gower - Pulmonary Rehabilitation services

Nicola Perry-Gower gave a presentation on pulmonary rehabilitation looking at the evidence vs the provision of services. In many areas PR has been chronically underfunded.

COPD is the third leading cause of death globally but is treatable and preventable.

Pulmonary rehabilitation is defined as:

“...comprehensive intervention based on a thorough patient assessment followed by patient tailored therapies that include, but are not limited to, exercise training, education, and behaviour change, designed to improve the physical and psychological condition of people with chronic respiratory disease and to promote long term adherence to health-enhancing behaviours” (Spruit 2013).

PR promotes autonomy and improves quality of life. Education component focussed on self-management, whilst the physical component focussed on increasing activity.

Modern pulmonary rehabilitation was trialled and rolled out in the mid-1990s and the cost benefits proven at Llandough Hospital in the early 2000s.

Pulmonary rehabilitation can:

- PR can reduce COPD exacerbations by 36%
- If every eligible person was referred for PR exacerbations could fall by a third
- This would reduce hospital admissions by 13%
- Halve the length of time in hospital
- Save 106,000 hospital bed days
- Reduce social care costs and free up GP appointments

To patients it means they can get out more, play with the grandchildren and have a better quality of life.

Pulmonary rehabilitation should be based on an MDT including specialist nursing, physiotherapy, occupational therapy, dieticians, PR technicians and exercise instructors, but many areas don't have this provision. Rural areas were trialling virtual PR and a hub and spoke model.

The pandemic stopped services and encouraged teams to innovate. Staff were initially redeployed. When they returned, they tried to encourage self-management at home and phone assessment. Powys were one of the first places to deploy virtual PR to milder COPD patients. Other areas found that hospital gyms were taken away. Community venues are being looked at, but many teams don't have the resources to afford these venues and availability is challenging. Even before 2020 some areas had waiting lists of over a year, now Betsi Cadwaladr UHB have 2 year waiting lists and Hywel Dda 3 years.

Long COVID created further challenges as these additional patients needed support as well.

The future is a mixed approach. Some people want virtual sessions to continue, many younger people can use the apps, but most need face-to-face support. There is a rich body of evidence to support pulmonary rehabilitation, but it needs health boards to invest in it. We focus a lot of on COPD, but people with IPF, Bronchiectasis, Long COVID and severe asthma can benefit as well.

After the presentation Nicola responded to some questions in the meeting chat. There were questions about how people got referred into pulmonary rehabilitation and about the challenge of space being taken away and PR not being able to restart.

5. Ruth Evans and Tracy Cross - Patient experiences of Pulmonary Rehabilitation

Ruth Evans shared her experience of getting diagnosed with IPF and how pulmonary rehabilitation had helped.

In 2017 she has severe breathing problems. The HCPs queried IPF, late onset asthma and Allergic Bronchopulmonary Aspergillosis (ABPA), but eventually after referrals to Morriston and to the Royal Brompton, IPF was diagnosed and treatment started.

She was referred to pulmonary rehabilitation for 10-12 weeks led by a specialist nurse & physiotherapist in 2018. She was then referred to the National Exercise Referral Scheme (NERS) via clinic, attended local classes weekly June 2018 until March 2020. This was a mixed group with other lung conditions and heart failure patients.

When lockdown started, she became aware of Carmarthenshire Council's Actif Anywhere, an online NERS classes. She attended twice a week and at £10 a month.

During 2021 she was prescribed ambulatory oxygen and has been able to manage this and all aspects of her treatment through the Patient Knows Best (PKB) system being rolled out in Hywel Dda.

She concluded by saying that her personal experience had been very positive, but she is aware that there are other parts of Wales with less support available.

Tracy Cross shared her story. She talked about starting to get breathless in 2014 following her pregnancy and Caesarean section, but it didn't improve in 2015 and finally in 2016 she was formally diagnosed with COPD. Her GP felt she was very young to have COPD and referred her to a consultant who thought she had asthma as well, and she was prescribed appropriate inhalers and referred her to pulmonary rehabilitation. Before PR she had struggled to even walk round the doctor's office. She was suffering from depression as it impacted on her daily life. PR made a huge difference.

In 2018 she started virtual running to keep herself fit and build on what she learnt at PR.

In 2019 she took part in a sponsored climb of Snowdon at night to raise money for British Lung Foundation, something that seemed unthinkable in 3 years previously.

In 2020 Tracy had COVID-19 but recovered and used her PR experience to help rehabilitate herself.

She thinks that everyone with a lung condition should have access to pulmonary rehabilitation and gave the example of her husband not being able to access it.

John Griffiths MS thanked Ruth and Tracy for sharing their stories.

6. Dr Simon Barry - National Respiratory Toolkit

Simon wanted to use his presentation to broaden the discussion and talk about the integrated system approach at a national level.

From policy to patient through a national platform:

- National Clinical Guidelines - endorsed by AWMSG and rolled out across Wales
- Standards and Education - 10,000 HCPs are signed up to training programmes and engaging with remote learning
- Quality Improvement - based on the NACAP audit we can support HCPs to improve locally and improve outcomes.

- Patient self-management apps - 30,000 people are using the COPD, asthma, and asthma for parents apps. The self-management videos and support can be accessed through the apps. The apps include Monthly checker, My care plan, wellness dial, and GP/hospital visits. They are also completely bilingual. The patient apps also include exercise videos and led by physiotherapists.

Simon thanked all the HCPs from across Wales who helped develop the apps and talked about the online education that has been provided during the pandemic:

- Addressing COVID vaccine safety concerns
- It's even more important to get a flu vaccine
- What to expect from a virtual consultation
- What to do if you have a flare up of your lung condition during the pandemic?
- Wearing a face covering if you have a lung condition
- What happens during inactivity, and tips for going for a walk
- How to regain control of panicky breathing
- Top tips for staying well in winter

Simon encouraged everyone to download the apps and try them out, whether they have a lung condition or not. He said the apps were far better than anything offered in the private sector and encouraged everyone to promote them.

He concluded by reminding everyone that there were no national guidelines, apps and education programmes in England, Scotland, or Northern Ireland, and that we should be proud of what has been achieved.

Action: Joseph to draft a letter for John Griffiths to send to the Minister for Health and Social Care raising the concerns from the meeting.

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 10 May, and that the theme would be asthma.

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.