

Meeting of the Cross Party Group on Lung Health

12 June 2018 5.30pm-7pm

CR4 Scottish Parliament

MINUTES

Attendance

MSPs

Emma Harper MSP (Convener)

Mark Ruskell MSP (Co-Convener)

Members and guests

Claire Shanks	British Lung Foundation (Scotland)
Alison Sweeney	British Lung Foundation (Scotland)
Joseph Carter	British Lung Foundation
Graeme Sneddon	British Lung Foundation
Katherine Byrne	Chest Heart & Stroke Scotland (CHSS)
Jill Adams	Chest Heart & Stroke Scotland
Allan White	Chest Heart & Stroke Scotland
Alison Jardine	Chest Heart & Stroke Scotland
Hazel Webb	NHS Lothian
Nicola Roberts	Glasgow Caledonian University
John Lockhart	University of West Scotland
Susan McNarry	NHS Lothian
Susan Mullen	NHS Lothian
Jacques Kerr	Scottish Government
Linda Gray	NHS Borders
Mostyn Tuckwell	Breathtakers Action for Bronchiectasis
James Wildgoose	Breathtakers Action for Bronchiectasis
Jane Ferguson	Ettrickburn Ltd
Phyllis Craig	Clydeside Action on Asbestos
Linda McLeod	Breatheasy Clackmannanshire
Gordon Thomson	Braveheart Association
Elaine Mackay	NHS Greater Glasgow & Clyde
Phyllis Murphie	NHS Dumfries & Galloway
Andrew Deans	NHS Lothian
Amanda Whiffin	Dolby Vivisol
Lesley Hill	Dolby Vivisol
Martin Charters	Patient representative
Damian Crombie	Astrazeneca
Graeme Brysen	Royal Pharmaceutical Society
Sally Hughes	Teva
Susan Cameron-Nielsen	Royal Pharmaceutical Society
Maggie Gallacher	Observer
Marion Ferguson	Observer
Jackie Baillie MSP	Observer
Kenryck Lloyd-Jones	Chartered Society of Physiotherapy

1. Minutes of last meeting, 6 February 2018

Agreed.

2. Update on progress since last meeting

2.1 Emma Harper noted the Group's appreciation for Irene Johnstone's work in driving forward the lung health agenda in Scotland. Joseph Carter is now Head of Devolved Nations at British Lung Foundation, overseeing the work in both Scotland and Wales.

2.2 Joseph provided an update from Dr Tom Fardon about his progress in developing the new Respiratory Care Plan. The Chief Medical Officer's 'Realistic Medicine' agenda will provide a unifying theme across the new plan. An early draft is intended to be available by early 2019. A core Steering Group is being formed, with membership including British Lung Foundation, Chest Heart & Stroke Scotland, Asthma UK and the Royal Colleges. Tom is keen that the Cross Party Group will have a role in driving forward the development of the plan, as will the broad range of agencies who will be delivering it.

2.3 Emma Harper provided an update on Parliament's debate on Orkambi, the cystic fibrosis drug. Nine MSPs were speaking in debate. Interim access to Orkambi was being pushed for whilst negotiations for a long-term solution are taking place. A previous meeting had been held at Parliament on Orkambi, with 15 MSPs attending from across parties.

2.4 Phyllis Craig from Clydeside Action on Asbestos updated members on the Members' Bill currently out for consultation which seeks to allow the NHS to recover medical costs of treating people suffering from industrial injuries and disease, including asbestos-related diseases. The Bill is being taken forward by MSP Stuart McMillan. Clydeside is also to sponsor 2 nurses, one for asbestos conditions in Edinburgh, one in Glasgow in Pleural Unit (to be advertised).

3. Research into Pulmonary Rehabilitation

Presentation

Leandro Mantoani gave a presentation on the findings of his PhD research on Pulmonary Rehabilitation and new technologies to counteract inactivity's presentation.

- COPD causes breathlessness and muscle weakness, leading to inactivity an issue and more time being sedentary. But low PA levels mean there is a higher chance of hospital admission and exacerbations.
- Some interventions can tackle inactivity. Leandro undertook a systematic review of 2,500 articles, narrowed down to 60 studies, to explore the interventions that would positively impact on activity levels.
- The findings suggest that where PR programmes are less than 12 weeks in duration, half of participants show positive change, and half no change on activity levels. But where programmes are longer than 12 weeks, patients are subsequently more active in their daily lives. People need 3 months to train their muscles, but 6 months to change behaviour.

- Leandro subsequently explored the impact of using activity monitors in increasing activity levels in patients undertaking PR. Forty-four patients were randomly assigned into control and study groups. The study group received a physical-activity enhancing programme, wearing activity monitors to measure all movements. Patients were set daily targets and these could be monitored each day, providing regular feedback to patients. Leandro monitored their activity levels via laptop, and provided support and encouragement.
- A comparison of the 2 groups shows that the Intervention group showed better increments in exercise capacity, and were fitter at end of the programme, with improved muscle strength. They took more steps, and reported reduced levels of anxiety and depression, and improved quality of life.
- In conclusion, longer PR programmes are more effective, ideally over 3 months, and there are benefits in combining programmes with a physical-activity enhancing programme. These findings have implications for the future delivery of PR programmes.

4. Round-table discussion - how can improvement in the delivery and participation in PR programmes be driven forward?

[During the discussion, Jackie Baillie MSP and family members from the Orkambi debate arrived to observe the CPG discussions, and were welcomed by Emma Harper.]

The key points raised have been ordered thematically below:

Current position

- Emma Harper – asked whether there are variations in delivery of PR in Scotland.
- Jill Adams – results of survey by Chest Heart & Stroke Scotland and SPRAG show **wide variations**. Duration varies between 6-15 weeks, some areas run block programmes instead of rolling programme. Good that the NACAP audit is coming to Scotland, which will give a lot more detail.
- Jill Adams - Need to keep focus on improving the reach of PR and participation rates – third sector important after completion. What is working well in different areas, examples of successful participation?
- Andrew Deans – wide variation in duration of PR programmes from between 6 and 15 weeks – Leandro’s evidence suggests the **longer the better, ideally 2-3 times a week**.
- Joseph Carter – standard from BTS is 6-8 weeks. **If programmes are longer is it about continuing exercise**, is the education component complete by then? Physical activity can be continued by individual. Interesting to look at an inverse pyramid of the percentages of people **accessing** different treatments eg PR and smoking cessation (as opposed to the cost-effectiveness of each).

Health professional awareness:

- Phyllis Murphy – Lack of awareness among health professionals, and the **difficulty of translating awareness at primary care level into referrals to services**.

- Jacques Kerr – chaired a national group for Scottish Government looking at unscheduled COPD admissions for 18 months. Jacques is not a respiratory specialist and learning about the benefits of PR had been an eye-opener - clinicians are usually focused on their own clinical territory. **Acute doctors are probably not aware of the benefits of PR.** There are huge benefits to managing anxiety and depression, not just physical benefits. The peer support aspect is hugely important. If financing PR is the problem, then there are good balancing measures in mitigating the cost of acute treatment. **Need to raise awareness among non-respiratory physicians.**
- Emma Harper– asked if there a Learn Pro module available for GPs to raise awareness? One is being started in Lothian.
- Jill Adams – CHSS is currently developing an **online training resource for health and social care professionals** called Resp-e – this is aimed at non-specialists, and will be available by the end of the year.
- Jacques Kerr – there is no clear reference to PR in the medical training syllabus. **Need to raise awareness** through the Royal Colleges, NES, getting medical students and other HPs referring people to PR.

Patient participation:

- Andrew Deans – Patients in clinical trials usually from primary care. When asked about PR, the majority have **never heard of it.**
- James Wildgoose - is PR generally available for people with **bronchiectasis**? Do people stay on courses to complete them. Leandro’s research demonstrates the importance of **ongoing motivation**, as it is often so much easier to medicate.
- Leandro Mantoani – there is a **behavioural/psychological aspect** to completing PR. Action after programmes complete is important in keeping people fitter for longer, such as support for self-management, home rehab.
- Susan McNarry – people want treatment in the community. Also, as a country of **serial non-exercisers** it is difficult to encourage people to participate if eg in 70s and have never exercised.
- Joseph Carter – **role of local authorities in keeping people active** is so important. Engaging and motivating people in physical activity is hard. Barriers to people participating, particularly costs after free PR finishes.
- Nicola Roberts – PR is not just about physical activity but important to also remember the education and advice components. It is a package of care. COPD patients have more problems with rehab than eg cardiac rehab. Having looked at the **reasons for non-**

completion of PR it isn't lack of motivation, but can be repeated infections, family problems, etc.

- Jill Adams – the **terminology used is a barrier to patients** – ‘Pulmonary Rehabilitation’ is not meaningful to most people. Is it time for a **change of name**?
- James Wildgoose - **peer influence** is very important, and the **voluntary sector** have a key role to play in that.
- John Lockhart – clinical background in osteoarthritis, and there are similarities with getting people to engage with **non-intuitive solutions** eg exercising – patients feel fobbed off.

Workforce

- Andrew Deans – having a nurse consultant in place (like Phyllis in D&G) – does it make a difference – **are we missing key people?**
- Phyllis Murphy – education should be written into job description. Lung health is higher on the radar. Jacques’ document - example of best practice in COPD care in Scotland.
- Joseph Carter – issue of educating health care professionals. In local areas if capacity is sufficient, can go out to practices. New audit of PR will look at success of education, as well as PA. Putting **motivational interviewing techniques** into practice is difficult – participants are sometimes put off by education.
- Susan McNarry?– undertaking a **review with SPRAG** looking at how education is delivered, topics, how much time, lead person, materials used, etc.

Examples of success/ideas for improvement:

- Nicola Roberts – **Value of expert patients** to shout about value of PR to other patients.
- Phyllis Murphy– NHS Dumfries & Galloway have now invested in **doubling the PR and Community Respiratory team**. Has had staffing issues, and a bad flu epidemic last winter. Got together with GP MCN colleagues to make water tight business case to invest so could go upstream and **deliver PR early on, preventing admissions** to avoid another winter situation. Have expert patients. Happy to share business case with other health boards.
- Andrew Deans – is PR not on radar because it's done in the community rather than acute settings? Physios could catch patients and inpatients and **begin PR early in hospitals**, but there is not funding for that, and always a push to get inpatients out quickly.

- Linda McLeod – members of the Clackmannanshire Breathe Easy group have mostly been referred to PR by their GPs. PR there a 6-weeks course delivered from Larbert Hospitals through **tele-health**, linking to a community health centre.
- Gordon Thomson – the Braveheart group provides rehab across Forth Valley. One lesson that Braveheart has learned – **important to build a community within the rehab** being delivered as it keeps people coming along.
- Kenryck Lloyd-Jones – Chartered Society of Physiotherapy is launching a public facing campaign coming ‘**Love Activity Hate Exercise?**’ – geared towards the message that exercise does not necessarily mean climbing mountains. Respiratory conditions are one of main reasons people don’t participate in exercise.
- Jacques Kerr – example of **Ayrshire** work around technology-enabled care and supporting PR. Instead of having a cold referral to a PR service, the physio spoke to patient and explained PR in detail, increased engagement of 20% to 53% completion rate. **Human element important.**
- Martin Charters – people don’t understand what PR is, it often isn’t explained to them, and given no evidence of the difference it makes. Martin has created a video for NHS Dumfries & Galloway **explaining PR, and actively speaks to class members about completion.** Seeing improvement in completion rates.
- Phyllis Murphy – her team in NHS Dumfries & Galloway all actively encourage and promote PR, explaining what it is and why it’s important. Hopefully the new national improvement plan will have PR in there as a requirement of Boards.
- Andrew Deans – important to note that one hat doesn’t fit all with PR, depends on condition, eg ILD, COPD. **Needs to be tailored for different groups.**
- Elaine Mackay – **NHS Greater Glasgow & Clyde** advocated referrals to PR from primary/secondary care, go to all GPs and practice nurses to make aware of the service, selling PR based on individual needs, which might be breathlessness, recurrent chest infections. **Last year had over 1000 referrals from primary, 1300 from secondary care.** Change happened over time – 2012 saw **changes in GP practice** in managing COPD patients - had to see once a year, every practice nurse had to attend a day’s **training.**
- Jacques Kerr – there are powerful **statistics which make the case for PR** – 122,000 occupied bed days attributed to COPD. Board need another 120k bed days by 2034. Need to align this with **Realistic Medicine**, making it about shared decision making, reducing harm and variation, being innovators and improvers.

5. Next Steps

- Secretariat - Share Martin Charters’ video promoting PR to patients (available on YouTube)

- Emma Harper/Secretariat - Write to CMO Catherine Calderwood about the issuing of education and training across the medical professions.
- All/Secretariat - Health & Sport Committee could consider evidence on the savings made through PR and impact of PR as an intervention, to include within their finance considerations.
- Secretariat - Report to Dr Tom Fardon and Scottish Government lead officials on the key points raised during meeting.

6. Proposal for meeting schedule and topic discussions

Option to hold joint meeting with CPG on Heart Disease and Stroke on Air Quality, in September.

7. AOB

None.

Meeting closed.