

# Cross-Party Group on Lung Health

## Minutes of Meeting – 15 November 2021

MSPs Attending: Emma Harper MSP, Alexander Stewart MBE MSP

External Attending: Gareth Brown, Joseph Carter, Heather Gordon, Andrew Cumella, Agnes Whyte, Andrew Deans, Colin Brett, Damian Crombie, Garry McDonald, George Davidson, Graeme Rose, John Lockhart, Judith Colligan, Katherine Byrne, Liam Clutterbuck, Linda McLeod, Liz Mason, Mark Dodd, Martin Charters, Martin Coombes, Phyllis Murphie, Maureen Ward, Stephen Chinn, Margaret Stevenson, Martina Chukwuma-Ezike, Sally Hughes, Susi Shanks, Nicola Roberts, Steven Adair, Lesley Hill, Jill McLeod, Brian Forbes.

Apologies: Mark Ruskell MSP, Andy Currie, Gordon Thomson, Julie MacDougall, Mostyn Tuckwell, Alan Kirk, Pamela Kirkpatrick, Jo Broomfield, Kimberley White.

*Note: The recorded meeting can be viewed at the Asthma UK and British Lung Foundation Scotland Facebook page - [CPG on Lung Health - 15 November 2021](#)*

### 1. Welcome and Introductions

- Alexander Stewart MSP welcomed the strong representation of people from across the respiratory sector and those living with lung conditions. AS noted that the main theme of today's meeting is COPD, given World COPD Day takes place on 17 November.

### 2. Minutes of Previous Meeting

- AS asked if there were any issues to be raised from the minutes of the previous meeting. None were highlighted.
- AS then asked Gareth Brown if there were any apologies submitted ahead of the meeting. GB confirmed there was and these would be included in the minutes from today's meeting.

### 3. COPD Presentations

#### Andrew Cumella – Asthma UK and British Lung Foundation

- AS then moved onto the main topic of discussion, which was COPD, noting that Emma Harper MSP has lodged a motion for debate on World COPD Day and that Gareth Brown would be in the Scottish Parliament that week to engage with MSPs around the COPD survey by Asthma UK and British Lung Foundation (AUK-BLF).
- AS thanked the speakers ahead of the presentations and introduced Andrew Cumella, Senior Analyst from Asthma UK and British Lung Foundation, who provided a presentation titled 'Failing on the Fundamentals – Our COPD Report'.
- AUK-BLF carried out new research and a survey, which was previewed to the CPG.
- AC reminded the CPG what COPD and how it is perceived, linking it to smoking, air pollution and employment history.
- AC pointed out that there are an estimated 138,000 people living with a COPD diagnosis and it is the 5<sup>th</sup> highest cause of death in Scotland.

- AC was responsible for a survey carried out between December 2020 and May 2021 on the care provided for COP and the impact of living with COPD. 652 responses in Scotland from 8232 across the UK.
- AC previewed the title of the report which was due to be published on Tuesday 16 November, ahead of World COPD Day, and pointed out that there were plenty of opportunities to raise COPD awareness.
- Headline stats from the survey and report showed that 17.2% of people in Scotland reported that they received the five fundamentals of COPD care in Scotland, compared to 24.5% across the UK. AC said that he was unsure what the stats would show initially and that across the UK this was a shocking finding.
- AUK-BLF surveyed on the number of exacerbations of COPD symptoms people had in the previous 12 months and the data showed that more people in Scotland (32.2%) are having 5 or more exacerbations than across the UK (27.3%).
- AC said this showed the need to have a self-management plan in place for people with COPD as only 65.8% in Scotland said they knew what to do in the event of an exacerbation.
- The following slide shows that smoking cessation is the highest value intervention that can be made to treat COPD. Again, Scotland has poorer rates of people being offered smoking cessation support than the rest of the UK.
- AC also stressed that not everyone with a COPD diagnosis has a history of smoking tobacco.
- The survey presented findings on the social, family and work impact of having a COPD diagnosis, with people having to stop working or reducing their working hours.
- AC then presented quotes from people with COPD facing discrimination and stigma.
  - 47.8% of people with COPD in Scotland think that there is a stigma attached to living with COPD and 29% said they has faced stigma and/or discrimination for having COPD.
- AC said this showed a lack of understanding around COPD and the impact this has.
- AC highlighted the policy calls from AUK-BLF in response to the survey:
  - Fully restart spirometry and pulmonary rehabilitation.
  - Implement Very Brief Advice for smoking cessation across primary care.
  - Ensure the five fundamentals of COPD care are offered and delivered.
  - Fund the Respiratory Care Action Plan.
  - Renew COP Best Practice Guide
  - Invest in Public Awareness Campaign to improve understanding of COPD.
- AC then asked the CPG for any questions following his presentation.
- AS said that some of the stats were startling and that long-standing concerns showed the need to raise awareness of the disease.
- Garry McDonald said that he believed that smoking cessation was doing better in Scotland, given the public funding. GM also shared links on smoking cessation in the Zoom chat function. GM asked AC why the figures are showing Scotland is lagging behind.

- John Lockhart followed on from the previous questions, adding that all the indicators are showing that Scotland is doing better with smoking cessation and asked if there was a reason why the devolved nations are performing poorer than expected.
- AC referred to the asthma survey which continually shows variations across lung health and the responses were informed by people in the survey.
- Phillis Murphie raised that the Respiratory Care Action Plan is being invested and that commitment is there to look at these issues. PM also said the survey respondent numbers were disappointingly low.
- Andrew Deans offered a patient perspective with a quote from a patient on her experiences and stigma saying that “each year my world gets smaller”.
- Nicola Roberts asked if the survey will be run annual or if this is a COVID blip. AC responded to say that is the hope in order to track changes through the years.
- Liz Mason asked how the Scottish Government are funding investment in supporting patients live normal lives with lung conditions as people suffer living with the conditions.
- Emma Harper asked about the survey numbers and how we reach out to get more people to respond to the survey. EH also asked about pulmonary rehabilitation in relation to the survey.
- AC responded to say that this was the biggest survey done for people with COPD and the length of the survey took 10-15 minutes to complete, providing a rich source of information to get a better picture of COPD care. On PR, Andrew said he would share further data where possible and that Joseph Carter or Gareth Brown would know more about what is happening on the ground in Scotland.
- Mark Dodd asked about a better accuracy of COPD diagnosis through COVID-19 restrictions. AC responded to say that the report calls for better diagnostic testing to reach more people and reduce the backlog, however that is down to the NHS to deliver this.
- Martina Chukwuma-Ezike asked about inhaler use from her experience in supporting people with asthma and Andrew responded to say he agreed that teaching correct inhaler use for COPD patients is vital.
- Joseph Carter thanked Andrew for presenting, adding that this is the first of three presentations he is doing this week. JC pointed out that a survey is not an audit and that this is the biggest sample size of COPD patients. JC said he would like an audit to provide more data to understand where COPD care and that the survey from AUK-BLF is a baseline.
- Katherine Byrne highlighted the work of Chest Heart and Stroke Scotland in working with health boards to get people holistic support to stay out of hospital. Kath asked what the impact of ending shielding and heading through winter will be for people with COPD and any possible exacerbations of COPD.
- AS summed up the conversation and moved to welcome Linda McLeod, a member of the CPG living with COPD, who is involved in the Breathe Easy Clackmannanshire group.

### Linda McLeod – COPD Experience

- Linda McLeod stopped smoking in 2000 due to a family bereavement. She noted that watching a loved one die from a lung disease is not a pleasant experience.
- LM was in disbelief when diagnosed with COPD, thinking quitting smoking and living a healthier lifestyle would avert any problems.
- LM spoke about what her experiences of the first symptoms and stages of COPD, which she said can sneak up a person but the sooner the diagnoses the better.
- To live the highest quality of life, everything changed with lifestyle and how she looked after herself following her diagnosis.
- LM spoke about tiring easy and having to plan an outing such as not travelling alone or driving far from her home. Stresses such as journeying can also make LM breathless.
- LM said that it is hard to convince people she is seriously because she looks well, with one person saying a change of diet may improve her illness. She also faces stigma and discrimination when shopping or parking because she looks well at the time, without people knowing it is a hidden illness.
- In recent years, LM has suffered other medical problems around eyesight and soke about the mental health impact of a lung health diagnosis.
- LM is chair of Breathe Easy Clackmannanshire and plays an active role in supporting other people with lung conditions, while also supporting other family members of patients to better understand their diagnosis.
- LM said that many people with lung conditions downplay their illness.
- Being a part of the CPG is a source of pride for LM and she spoke about the opportunity to talk about her lung health and meet wonderful people in the CPG.
- Breathe Easy members recently starred in an NHS video and LM encouraged everyone to watch it.
- LM highlighted an instance where someone confused her COPD with OCD, showing the lack of understanding around the illness.
- LM wants to spend her time educating people about lung diseases and encourage young people not to take up smoking, regularly speaking with schoolchildren pre-pandemic.
- LM finished to say she will not give up or give in to her illness.
- AS offered his gratitude to Linda for her talk about living with COPD and raised how respected Linda is locally in her passion for improving awareness and reducing stigma, labelling Linda a “trailblazer”.

### Judith Colligan – Scottish Pulmonary Rehabilitation Action Group

- Judith Colligan is a respiratory physiotherapist from NHS Highlands. Her presentation is on the challenges and barriers to delivering pulmonary rehabilitation (PR) during the pandemic and subsequent lockdowns.
- Judith spoke about the aims of PR, which are to prevent deconditioning, restoring medical, emotional, social and vocations potential. The slide showed a spiral of disabilities which can occur when PR is not available.

- Judith gave a case study of a patient before the pandemic who was hospitalised and then discharged, causing isolation. She was referred to PR and performed shuttle walk test, managing only 10 metres. After completing the PR course, she could then complete 150 metres. Six months later she was completing 200m and meeting friends on social outings. She was still reporting breathlessness but was no longer afraid to go outside.
- Judith talked about the effects of shielding, some of which were increases in breathlessness and deconditioning and isolation.
- SPRAG held regular online meetings to discuss PR. Most areas managed to continue delivering some form of PR, although it was not face-to-face. Some staff were redeployed to other areas.
- The main forms of PR were through phone contacts to offer advice, signpost resources and support for home exercise, with some home visits and one to one PR sessions continuing.
- Judith pointed out that virtual classes became the norm during the pandemic, using different platform. Around one-fifth of patients opted to trial online classes, with many waiting for face-to-face to resume.
- The overall opinion was that virtual classes worked well according to Judith.
- Judith reported at the end of 2020/beginning of 2021, the remobilisation of face-to-face classes was planned. New guidelines are in place, with variations on number who can attend due to risk and infection protocols.
- There has been limits place on class sizes which will have an impact on waiting lists, although some classes are now running twice per week, with home exercise programmes encouraged.
- Judith stated that assessment options for delivery are discussed to be of best benefit of the patients. Many patients are not keen to return to face-to-face groups. Hybrid classes have been used.
- Judith highlighted some of the barriers to delivering PR services, such as lost space due to hospitals using gym space, some spaces such as local authority control leisure centres having to go back to tender and also staff being redeployed elsewhere within the NHS throughout the pandemic.
- There have been lots of things learnt throughout and Judith reflected on some of what has been learnt such as utilisation of virtual classes etc.
- Judith then asked for any questions and Alexander Stewart opened the discussion up for questions.
- Nicola asked about patients falling because of deconditioning and isolation. Judith responded to say they are assessing at all levels, especially when coming into the hospitals and there has been an increase in frailty.
- AS thanked Judith and asked for one more question. Emma Harper then said that the deconditioning and frailty has been raised at the previous Health and Sport Committee and thanked Judith for her presentation.

#### 4. Respiratory Care Action Plan

- AS handed the meeting over to EH. Emma thanked everyone for their great presentations so far. EH commented that Dr Tom Fardon did not appear to be on the call, however asked Prof John Lockhart to talk instead about his work in schools to prevent smoking.
- JL talked about his work in the south-west of Scotland in primary and secondary schools, which has built momentum in recent years. Using younger PhD students, they go into schools and talk about COPD and what it feels like.
- JL said that involving patients in school talks is a great innovation and pupils were thoroughly engaged because of the shock and direct insight of living with COPD.
- Working with schools is hopefully useful in the long run as part of prevention models to reduce smoking rates in younger people.
- Phyllis Murphie and Joseph Carter provided short updates on the implementation of the Respirator Care Action Plan in absence of Dr Tom Fardon.
- Steven Chinn asked about patient access to the RCAP groups discussed by PM, with Katherine Byrne responding to say that there is a meeting due to be held on 14 December that will create the patient working groups.

#### 5. Date of Future Meetings

- EH said that Monday mornings may not be best for future meetings. EH asked for the next date of the CPG meeting to be polled. Gareth agreed to send around a Doodle poll to see when the most suitable days are.

#### 6. AOCB

- None

#### 7. Close of Meeting

- Emma Harper thanked all the speakers and Gareth Brown for the successful meeting today and said that the CPG should be looking to invite the Public Health Minister Maree Todd MSP.
- Finally Emma encouraged everyone to listen to the World COPD Day on Tuesday 16 November.