Meeting of the Cross Party Group on Lung Health
6 February 2018 5.30pm-7pm
CR4 Scottish Parliament

MINUTES

Attendance

MSPs
Emma Harper MSP (Convener)
Alexander Stewart MSP (Co-convener)

Members

Irene Johnstone	British Lung Foundation (Scotland)
Claire Shanks	British Lung Foundation (Scotland)
Alison Sweeney	British Lung Foundation (Scotland)
Katherine Byrne	Chest Heart & Stroke Scotland (CHSS)
Jill Adams	Chest Heart & Stroke Scotland (CHSS)
Dr Fergus Donachie	NHS Dumfries and Galloway
Phyllis Murphie	NHS Dumfries and Galloway
Linda McLeod	Breathe Easy Clackmannanshire (BLF Scotland)
Agnes Whyte	Breathe Easy Kirkcaldy (BLF Scotland)
Andrew Deans	Royal Infirmary Edinburgh
Mostyn Tuckwell	'Breathtakers' Action for Bronchiectasis (CHSS)
Ann Anderson	'Breathtakers' Action for Bronchiectasis (CHSS)
Colin Brett	COPD managed clinical network, NHS Dumfries and Galloway
Elaine Mckay	NHS Greater Glasgow & Clyde
Tom Fardon	NHS Tayside / STS / NAG
Pamela Kirkpatrick	Robert Gordon University
Caroline McNerney	Boehringer Ingelheim Ltd
Sally Hughes	Teva UK
George Davidson	GSK
Damian Crombie	AstraZeneca UKMC
Lesley Hill	Dolby Vivisol
Amanda Whiffin	Dolby Vivisol
Jane Ferguson	Ettrickburn

Guests

Fiona Mackenzie	Information Services Division, NHS National Services Scotland
Dr Gary Litherland	BREATH project

Apologies

Gordon Thomson	Braveheart Association
James Wildgoose	'Breathtakers' Action for Bronchiectasis

1. **New members**

- Pamela Kirkpatrick, Senior lecturer, School of Nursing and Midwifery at Robert Gordon University

- Damian Crombie and Ian Mullan, both from AstraZeneca. Ian is the National NHS Relations Lead - Respiratory, Inflammation & Autoimmune, while Damian covers both Scotland and Northern Ireland.

- Caroline McNerney, Medical Science Liaison Team Lead from Boehringer Ingelheim

- Dolby Vivisol – the oxygen providers for Scotland

2. **Minutes of last meeting, 21 November 2017 (AGM)**

Agreed.

3. **Update on progress since last meeting**

3.1 COPD Parliamentary Debate: The debate was deemed successful – a summary was circulated via email to members after the event. There was substantial BBC Live coverage of the debate and lots of social media activity. Thanks noted to Kath Byrne and Claire Shanks for tweeting.

3.2 Parliamentary reception: The World COPD Day event was a deemed successful, with around 50 in attendance. Thanks extended to all who came along or supported, with special thanks to Minister Campbell and the MSPs for coming along and for joining in so enthusiastically with the Singing for Lung Health choir.

Attendees heard from choir member Dorothy on the real difference that singing has made to her, as well as hearing from CPG member Linda. Both spoke honestly about the challenges of living with COPD and the importance of taking control. Dorothy and Linda were thanked for their valuable contribution.

3.3 AGM: Members were reminded that minutes of the AGM were shared previously via email. The CPG office bearers will continue, with the addition of Alexander Stewart MSP as Co-Convener, along with Mark Ruskell MSP. Rachael Hamilton has also joined as an MSP member.

3.4 **Taskforce for Lung Health:** Members were reminded that one of the drivers for establishing this CPG was to increase awareness on Scotland's lung health and to support the ask for a taskforce to consider and prioritise the issues and come up with a plan for change. Emma Harper received confirmation last week that Scottish Government is supportive of this and that Dr Tom Fardon will lead this work. Tom will update members as part of this meeting's agenda.

Alexander Stewart noted his thanks to the CPG for pushing for the taskforce.

4. Topic Discussion

4.1 Digital Optimisation, Fiona MacKenzie

Members were reminded that when the CPG was established, members identified key themes to discuss, one of which was data and information sharing. Fiona Mackenzie, Service Manager, Information Services Division, NHS National Services Scotland, will discuss the benefits and challenges of capturing robust data and will consider how we use information to shape and inform best practice, as well discussing how CHI and SPIRE can work to Scotland's advantage in driving health outcomes.

- Fiona explained that ISD is part of Public Health & Intelligence (PHI) within NHS National Services Scotland (NSS), a "special health board" within NHS Scotland.
- Majority of health statistics in Scotland produced by ISD Scotland, which has some of the best health data in the world, as well some social care stats. Though ISD acknowledges there is always room for improvement.
- Data is used for a range of purposes including service planning, policy, quality improvement, performance monitoring, financial allocations etc.
- ISD gathers data from "before conception to the grave", with IVF and maternity data collected. Most of the data sets collected offer 100% coverage and include child health, immunisation, GP consultations, A&E, prescribing, hospital admissions, outpatients, amongst others.
- ISD has analytic capabilities which allows them to drill down into the background of the data to understand why things happened, and how to plan for the future based on that information, for example, cancelled operations. A tool called System Watch can help hospitals plan capacity. Fiona stated that "If data is not used, then it is pointless collecting it."
- Fiona explained the process around data development ie. how decisions are made as to what data is collected, which includes looking at cost vs. benefit, and is overseen by the Public Benefits and Privacy Panel.
- Consistency in coding is key, to ensure that local and national mapping is accurate. However, there are difficulties around definitions.
- SPIRE, collected via GPs, is potentially the most comprehensive data source on the health of the Scottish population. Rolled out to most practices by Spring 2018 but currently fragmented in uptake by practices.
- If adopted fully, it could unlock this data source to help with patient care, service planning, needs assessment and research.
- Fiona showed members some stats on respiratory prescribing:
    - Almost 1.2m people were prescribed a respiratory related prescription in 2016/17
    - For every £8 spent on prescribing £1 is spent on respiratory drugs
    - At a total cost £131m (average of £110 per person)
- Community Health Index, known as CHI, allows patient data from across all levels of health and social care to be linked. Linking care and health data can be challenging due to some exceedingly complex patient pathways.

- Fiona showed interesting comparisons of the most common COPD pathways taken in NHS Tayside and NHS Ayrshire and Arran. Opens up questions as to why these pathways are taken, what are the differences in the boards?
- ISD wants to work with customers to "turn data into actionable intelligence".

4.2 Questions and discussion points

Andrew Deans: There are challenges for clinicians and researchers around accessing and having to pay for data, which they provided in the first place. There does not appear to be a clear pathway for users/customers. Curious also about process around disease registries.

Fiona Mackenzie: ISD priorities are largely agrees with /determined by Scottish Government priorities. This is why, for example, there is a diabetes disease registry. If pieces of work come in, ISD checks that this reflects core business priorities. If it does then they seek funding partners and look for existing data sets, to hopefully keep costs down. Fiona was happy to exchange contact details with Andrew in order to further discuss issues around data access.

Mostyn Tuckwell: Are other respiratory diseases such as bronchiectasis gathered by ISD?

Fiona: Yes, COPD and asthma were just used for illustration. If patients go through secondary care settings then the data should be very good. However, community and primary care is still lacking. Perhaps this is something the new taskforce could look into?

George Davidson: How are patient outcomes recorded, if at all?

Fiona: Qualitative data such as this is lacking, as it's very difficult to measure currently. Though there is obviously real merit in this data.

Tom Fardon: Even hard, quantitative data is difficult to interpret, because of the lack of the qualitative data behind it. For example, we might have the data on the number of exacerbations in a certain area, but they doesn't tell us why they happened. Need to be careful not to over interpret hard data. "Data needs to be front and centre in the taskforce".

Kath Byrne: Will we still see proactive publication of data sets?

Fiona: Yes, and possibly even enhanced.

Jane Ferguson: What areas is SPIRE being rolled out in? Is it phased?

Fiona: NHS Dumfries and Galloway were first to take it on, and hoping for 100% coverage across Scotland by April/May 2018.

Andrew Deans: SPIRE is opt-in, so is there an incentive for GP practices to start using SPIRE?

Fiona: The Royal College of GPs is very keen to start using SPIRE, so confident that this will influence practices. Slow initial uptake could be down to other practices waiting to see the benefits before choosing to get involved.

4.3 Scotland's lung health taskforce

The Scottish Government (ScotGov) has now committed to the introduction of a task force to improve Scotland's Lung Health. Dr Tom Fardon was asked to present to the CPG on the role, remit and priorities of the task force and how it will look to change Scotland's legacy of poor lung health.

- Dr Fardon said he was really pleased that since the CPG started pushing for a taskforce the Scottish Government has listened and committed to it.
- Dr Fardon talked through the previous input to / structure around the National Advisory Group (NAG) for Respiratory Managed Clinical Networks (MCNs). This includes feed-in from MCNs, though Dr Fardon is very worried about the current threat of losing MCNs in Scotland. It was very clear at the last meeting of the NAG that MCNs are hugely variable across the country, which is a bad thing because when MCNs are working they are hugely beneficial.
- Involvement of the third sector, professional societies, and patients are also incredibly important. Dr Fardon very pleased to see the growing number of patient reps sitting on the CPG.
- The lack of any substantive ScotGov presence or input to the NAG has always seemed "odd" and a "poor show". Despite all the passion and knowledge around the table, ScotGov has not seemed interested.
- Recent NAG priorities have been on education, asthma, oxygen and a Respiratory Quality Improvement Plan (RQIP).
- Despite huge effort of some key individuals, the RQIP made minimal progress over the last two years. This was due to a lack of ScotGov involvement – those in the NAG writing it didn't know how to write such a plan.
- In that time, the Welsh Government developed and launched a new respiratory plan.
- Around the time the CPG was formed, Dr Fardon felt there was a shift in ScotGov interest in respiratory. He highlighted the COPD Short Lift Working Group as an example. The CPG has also gone "from strength to strength".
- Dr Fardon confirmed that the NAG will continue but his primary focus will be the taskforce. ScotGov has agreed to pay him for the time he dedicates to this work.
- Dr Fardon is still unsure of the final membership of the taskforce but wants representation to be sufficiently broad but not so large as to be inefficient. A steering group at its head might solve this issue. He wants representation covering:
    - Paediatrics
    - Health economics
    - Sleep services
    - Primary care
    - Third sector
    - Research
    - Public health, amongst others.
- Dr Fardon does not want the taskforce to rehash guidelines or focus on accreditation. It should focus on the RQIP and quality standards, with the key audience for this being the Integration Joint Boards and Health and Social Care Partnerships. It should be for those bodies to use. Should there be rewards for good adherence?

- There are challenges in developing the RQIP – urban vs rural; big cities vs small cities; the balance and number of health boards, MCNs, HCPs etc; and of course, costs.
- Dr Fardon talked through some respiratory prescribing data to illustrate the point that significant cost savings can be made by being both bold and smart in our decision-making.
- The Quality in Primary Immunodeficiency Services (QPIDS) was used as an example of a style of document to possibly emulate for the RQIP. It clearly states the number of staff required per 1000 patients. Could this be done for respiratory? For example, "we need X number of PR classes and X number of specialist nurses per 1000 patients." Also, something as simple as demanding anticipatory care planning as a standard?
- Dr Fardon has identified the following as "low hanging fruit" –
    - Pulmonary Rehab
    - Pathways
    - Imaging
    - Specialist nurses
    - Sleep service
    - Anticipatory care plans
- Dr Fardon finished by stating that we would welcome input from CPG members.

4.4 Questions and discussion points

Irene Johnstone: We need to ask ourselves from the outset what exactly it is that we want this plan to achieve, which should then inform what the taskforce focuses on. If it's about tackling and reducing poor lung health in Scotland then it needs to have a strong preventative agenda, not just a focus treating disease.

Dr Fardon: Mindful of not speaking on behalf of a group (taskforce) that does not yet exist. The remit for the taskforce and the RQIP is still up for discussion and will hopefully be wide, and ideally will look at areas of prevention such as air quality.

Mostyn Tuckwell: Wants to see patient representatives on the taskforce, which Dr Fardon agreed was essential.

Phyllis Murphie: The taskforce should look to other existing plans for inspiration, such as the Welsh respiratory plan, which is very ambitious.

Dr Fardon: Agreed the Welsh plan is very impressive, but it raised the issue of being ambitious vs overreaching. He suggested that it might be wise to develop a plan that is ambitious but with achievable goals, so that ScotGov can be impressed and assured that funding the plan is worthwhile and will dedicate resource to it and future iterations for years to come.

Emma Harper MSP: Informed members that she is now a member of the Health and Sport Committee and has had the opportunity to mention the lung health plan, so that is now on the record. She has also written to ScotGov about the lack of pulmonary rehab in Ayrshire and Arran, as well as writing to ask about updates on the ban on smoking in cars with

children. Emma is happy to continue to raise any issues agreed by the CPG with ScotGov and at Committee.

Dr Fardon: Cancer will not be covered by the taskforce, as covered by other cancer strategies.

Irene Johnstone: Mesothelioma – this type of cancer is not included in the Scottish Government's Cancer Strategy so perhaps an exception could be made for this type of cancer? Dr Fardon will seek advice from Colin Selby on the matter.

Andrew Deans: Pleased to see research will feature in the taskforce work. He also raised issues around specialist nurses, saying that many nurses cannot afford to become specialists as it results in a pay-cut. Long-term workforce planning needs considered.

Fergus Donachie: Struggles with his local health board and finds them a barrier to change, despite presenting them with evidence on cost savings to be gained from introducing PR and specialist nurses. The board always agrees it's a good idea, but never actions it.

Dr Fardon: Agrees there are problems. Healthcare professionals have hitherto been trying to drive change from the bottom up. Now is the time for top-down change, hence the taskforce.

Irene Johnstone: Will the taskforce look at advancing technologie? Dr Fardon said that there is a lack of tech in respiratory at present, but argued that we need to "get the basics right first", things like PR, enough nurses, hospices etc.

Emma Harper: A Bill on HSC staffing going through Parliament at the moment, due to reach Health Committee in May 2018. This bill would be an appropriate place to raise some of these issues. Emma also said that there is a debate currently around nursing salary banding and what constitutes a "skilled" worker.

George Davidson (GSK): Asked members to look on pharma as a body that wants to help. He has taken on board the costs issue, as do all pharma companies. Understands the difficulties around transparency but very keen for those working in respiratory to consider pharmas as there to help. Dr Fardon keen to engage with pharmas but transparency is paramount.

5. Next Steps

5.1 The taskforce: Dr Fardon will be able to begin work on the taskforce when ScotGov issues first payment at the end of February. He has been pulling together a list of possible names for members – happy to have people come forward to join. He will update the CPG on progress of the taskforce at regular intervals – perhaps at meetings? He will also update the respiratory sector at the Scottish Thoracic Society meeting on 20 June, and at the MCN Learning Forum on 3 October.

5.2 Possible themes for future meetings:

- Public Health reform with a strong focus on improving health and reducing health inequalities
- Social Isolation /loneliness – to tie in with the Scottish Government's new draft strategy
- Air Quality
- Young people/paediatrics – to tie in with Scotland's Year of Young People
- Service innovation and research that will shape future practice

5.3 Future parliamentary event: Emma Harper reminded members of the great success of the last parliamentary event hosted by the CPG and suggests another, larger event should be held this year, perhaps in the Garden Lobby. The Secretariat will look into this and report back.

6. Proposal for meeting schedule and topic discussions

The next meeting of the CPG will be on **12 June 2018**, theme TBC.

7. AOB

Linda Gray update on pulmonary rehab provision in NHS Borders

After much work, greatly supported by Chest Heart & Stroke Scotland, NHS Borders is scheduled to finally get a pulmonary rehab programme by the end of February, though many challenges continue.

Linda says the "space and willingness" of the Board to deliver PR is there, but "the promise of money has yet to materialise". The Borders IJB said the PR programme proposal is still "not transformational enough", which Linda knows now to mean not cheap enough. She is therefore working on making the proposal cheaper. This is very frustrating when Linda knows that the Board and IJBs invest in other treatments that are more expensive yet have a much smaller/weaker evidence base than PR does. This is despite a letter from the Minister for Public Health and Sport to the IJB in support of PR.

Dr Fardon said that it is "outrageous and very short sighted" of the Board to not be embracing PR / demanding it be made cheaper. There is no MCN lead in Borders, which he argues is evident in cases such as this – there is no admin support for people like Linda trying to implement change.

Meeting closed.