Cross Party Group on Lung Health

Minutes of Meeting

18 September 2019

MSPs:
Emma Harper MSP (Convener)
Alexander Stewart MSP

Secretariat:

Frank Toner	British Lung Foundation
Katherine Byrne	Chest Heart & Stroke Scotland

Other attendees:

Edwin van Beek	Director Edinburgh Imaging Facility QMRI
Gourab Choudhury	NHS Lothian and University of Edinburgh
Alison Sweeney	British Lung Foundation
Allan White	Chest Heart & Stroke Scotland
James Wildgoose	Action for Bronchiectasis
Mostyn Tuckwell	Action for Bronchiectasis
Frank Sullivan	University of St Andrews
Mara van Beusekom	University of St Andrews
Jim Simpson	Action for Pulmonary Fibrosis
Brenda Massie	Action for Pulmonary Fibrosis
George Davidson	Glaxo Smith Kline
Martin Coombes	Bristol Myers Squibb
Andrew Deans	NHS Lothian
Linda Gray	NHS Borders
Nicola Roberts	Glasgow Caledonian University
Edel Clough	Primary Ciliary Dyskenesia Family Support Group
Anne Crilly	University of West of Scotland Breath Project
George Chalmers	NHS Greater Glasgow & Clyde
Tom Fardon	NHS Tayside
John Murchison	NHS Lothian
Lorraine Dallas	Roy Castle Lung Cancer Foundation
Melanie Mackean	SCAN cancer network, lung Chair

1. Emma Harper welcomed people to the meeting, and provided an update on recent developments including a debate to be held the next day at the Scottish Parliament on Idiopathic Pulmonary Fibrosis, and the creation of MSP Respiratory Champions for key chest conditions.

She advised the members that Lung Health Champions in Parliament have been established – Alex Cole Hamilton (bronchiectasis), Colin Smyth (IPF/ILD), Annie Wells (COPD), Mark Ruskell (Air Quality), Emma Harper (Asthma), Alexander Stewart (smoking cessation).

2. **Presentation on CT lung cancer screening by Edwin van Beek**, SINAPSE Chair of Clinical Radiology, Director Edinburgh Imaging facility QMRI, Honorary Consultant Radiologist, NHS Lothian

- Edwin highlighted Scotland's poor record on lung cancer, with a lack of improvement in survival rates. Lung cancer now kills more women than breast cancer
- There are challenges in detecting lung cancer, with small tumours not always being detected by chest x-ray. More advanced software tools can help pickup smaller nodules, though these will not always be cancerous
- Studies are presently looking at what screening works.
- The benefits of early detection include improved mortality rates, and cost effectiveness of early diagnosis and treatment.
- E-cigarettes are not a solution to smoking – they are still hazardous, and new reports about their effects are concerning.
- Mobile screening is taking place in England, though it is of lower quality than regular screening. There is currently no screening in Scotland, despite having a high risk population with smoking history. Scanning presents the potential to detect other lung disease such as COPD and cardiovascular disease.
- NHS Lothian is currently preparing a business case for piloting screening.
- There is a shortage of radiologists to carry out scanning, but there is scope to use software tools.

3. Presentation on trial of blood tests for early detection of lung cancer by Jack Sullivan, Professor of Primary Care Medicine, University of St Andrews

- Jack described a successful trial at St Andrews of using blood tests for early detection of cancer.
- The trial has reached phase 4, and has tested 12,000 patients, focusing on smokers. The main outcome aimed for was reducing late stage presentations of lung cancer. The trial has successfully achieved a 36% reduction, and reduction in all cause mortality.
- They now want to work with others in Scotland to see where using targeted blood testing in Scotland could have maximum effect, for example areas of greater deprivation where smoking rates are higher.

4. Presentation by Gourab Choudhury, NHS Lothian on the challenges of managing COPD – where we are, and where are we heading

- Gourab highlighted that COPD prevalence is rising across world, unlike other major causes of death such as ischaemic heart disease which is static. There are currently an estimated 1.2m people in UK diagnosed with COPD, which has a major socioeconomic impact
- COPD deaths are equivalent to around 1 death in every 20 in the UK, with smoking being the commonest cause. There are other aggravating factors, such as environmental factors, and an ageing population.
- In Scotland there is predicted to be a 33% increase over the next twenty years. COPD currently accounts for 6% of all deaths in Scotland.
- Steps are being taken to address this, through early detection, better detection, and greater uniformity and equity of care.
- COPD is significantly under diagnosed, but if diagnosed during early stages there are greater opportunities to tackle it. Methods of active detection include screening of high-risk populations, spirometry events etc.
- A cost effective model of good detection should be built on the pillars of Realistic Medicine, such as personalised care, reduced variation, and innovation
- An integrated healthcare system should include anticipatory care, management in the community as much as possible, hospital admissions only if necessary.
- Home management helps prevent complications, and avoid functional decline (which can begin within 48 hours).
- There are a range of ways to reduce emergency department admissions, including early pulmonary rehabilitation, technology enabled care, patient education and self-management plans.
- The Lothian COPD pathway has been redesigned to have a multi-disciplinary team within a community respiratory hub which puts the patient at centre. The model has significantly reduced admission rates, despite increased prevalence of COPD.
- Other examples of improvements include the Glasgow community respiratory team.
- The COPD Best Practice Guide, which is based on the '6 essential actions on unscheduled care' include an action effect diagram on improving COPD management.
- Communication between primary and secondary care is important. Key Information Summaries (KIS) are important and effective in recording patient history and their on resuscitation, admission, etc. Anticipatory Care Planning is another important aspect of COPD management.
- Moving forward, there is evidence of the benefits of high intensity exercise during pulmonary rehab, but current models are based on low intensity. Edinburgh ERI is trialling high intensity, capturing patients in hospital, then following up in community with conventional PR.

- Digital health can be effective in tackling tackle social isolation. NHS Lothian is trialling the My COPD App.
- Patients need to be stratified to their level of engagement with their illness. Lothian is trialling Patient Activation Measures to gauge if patients are passive or engaged, and take steps to activate them, PAM has been trialled in US and parts of UK, and can improves understanding of disease.
- In summary: COPD prevalence and mortality will continue to increase; detection and equity of care are key; non-pharmacological therapies improve quality of life; and patients must be a part of their own journey.

5. **Questions and discussion followed on a range of issues**:

- The long-term benefits of high-impact exercise in pulmonary rehab.
- Challenges of screening in more deprived communities, and the importance of trying different methods, making it easy to access, tackle the issue like bowel cancer has been, which saw an increase of screening rates from 10% to over 60%. St Andrew's University is looking at that issue, in particular opportunities to co-design solutions. Screening needs to be targeted at the right people, not the 'worried well'.
- The importance of the education component of pulmonary rehab, with recent unpublished research showing variations across Scotland. Patient activation measures can't be used in isolation.
- Dr Sue Payne from the Scottish Screening Team explained that screening policy in UK is set by national committee, which examines the evidence and cost effectiveness, economic and pathway modelling. There is an independent advisory committee to the four nations. Screening is not straightforward – there are only 6 national screening programmes. The NHS needs systems in place in order to invite the right people to screening and not miss them. There are ethical and legal considerations to be explored before implementing a screening programme . They are actively looking at lung cancer screening and waiting for evidence about target groups, and the right combination of tests to offer. There then need to be pathways to follow, including CT capacity, surgical time, ITU capacity.
- Edwin van Beek responded, highlighting that the results from the NELSON study already evidence a massive impact of lung screening. Other countries are going into lung cancer screening because they conclude that the evidence is athere. We are bottom of survival league, often because not reaching early enough.
- Jim Simpson from Action for Pulmonary Fibrosis highlighted that lung screening may present opportunities to diagnose other lung disease such as IPF, and the importance of early identification of conditions like fibrosis
- Gourab Choudhury noted that his COPD model could be a prototype for any lung disease, principles are exactly the same, early rehab of IPF patients, treatments to slow down.

- Edwin van Beek confirmed that 6 different types of COPD can be identified by CT, some overlap with IPF. NHS Lothian is ensuring quick diagnosis, by shortening delays in access to CT scans, involving GPs.
- The South East Cancer Network support lung cancer screening. The cost of treating stage 4 lung cancer has increased from £252 to £1,000. The cost effectiveness of screening is likely to be better than the NELSON study evidence shows. Immunotherapy and surgery are both expensive.
- The Roy Castle Lung Cancer Foundation noted that Scotland is failing to properly serve a deprived population. There is a need for education around lung disease. Funding for a service will follow the commitment to tackle.
- Dr Tom Fardon provided an update on the developing National Respiratory Action Plan. The draft will be submitted to the Minister within 2 weeks, and published for consultation by the end of the year. They anticipate finalising the plan by summer 2020.

6. Action Points:

- Write to Scottish Government supporting lung screening, and early pilot
- Write to SG to highlight work in NHS Lothian, and Dumfries & Galloway
- Spirometry testing event in Parliament in early 2020.
- Note positive developments - Lung Health debates in Parliament and appointment of MSPs as lung health champions.
- Future meetings to consider – Vaping; Inhaler techniques; Sleep Apnoea