Cross-Party Group on Lung Health

Minutes of Meeting – 27th September 2021

MSPs Attending:	Emma Harper MSP, Alexander Stewart MBE MSP, Mark Ruskell MSP
External Attending:	Gareth Brown, Joseph Carter, Heather Gordon, Dr Tom Fardon, Monica Fletcher, Hilary Pinnock, Aziz Sheikh, Claire Jankowska, David Weatherill, Noele Morgan Webber, Steve Chinn, Colin Brett, Wendy Inglis Humphrey, Katherine Byrne, Maureen Ward, Liz Mason, Susi Shanks, Liam Clutterbuck, Johnny Lockhart, Mark Dodd, C Thompson, Sally Hughes, Martin Charters, William McGhee, George Davidson, Agnes Whyte, Graeme Rose, Helen Reilly, Nicola Roberts, Aaron Gowson, Sara McArthur, Jo Broomfield, Linda Gray, Lesley Hill, Garry McDonald, Linda McLeod.
Apologies:	Dr George Chalmers, Pauline Waugh, Pamela Kirkpatrick.

Note: The recorded meeting can be viewed at the Asthma UK and British Lung Foundation Scotland Facebook page - Cross-Party Group on Lung Health September 27 Meeting

1. Welcome and Introductions

- Alexander Stewart MSP thanked and welcomed everyone for attending the Cross-Party Group on Lung Health.
- AS then moved on to the next agenda item and asked Gareth Brown to speak.

2. Minutes of Previous Meeting

- Gareth Brown thanked Alexander and asked the CPG if any member would like to request edits to the minutes from the previous CPG meeting in June.
- Gareth also highlighted that the meeting would be recorded and asked if any member had an objection to that.
- Alexander thanked Gareth and moved on to the next agenda item and asked Joseph Carter or Dr Tom Fardon to discuss the work of the Respiratory Care Action Plan. Both Joseph and Tom agreed that it would be better for TF to speak first.
- Tom said that his RCAP presentation would follow his Precision Asthma presentation.
- Monica Fletcher asked if Asthma UK Centre for Applied Research (AUKCAR) could present first. It was agreed that Aziz Sheikh would present first due to his time commitments.

3. Asthma Presentations

Asthma UK Centre for Applied Research

- Monica Fletcher introduced the speakers from AUKCAR and set out the agenda for the speakers. MF then handed over to Aziz Sheikh to speak first.
- Aziz Sheik thanked the CPG for the opportunity present as the lead of the AUKCAR, which is based in Edinburgh.
- Aziz then spoke about the '4 Urgent policy focused pieces of work – with a focus on asthma – during the pandemic.' These included 1) identifying adults at increased risk of COVID-19 hospitalisation and deaths 2) investigating the impact of lockdowns poon chronic respiratory

diseases 3) identifying children at increased risk of COVID-19 hospitalisations and deaths and 4) understanding risk factors for serious post-vaccination breakthroughs.

- Aziz highlighted how AUKCAR were working with the UK and Scottish Governments on the four urgent policy focused pieces and how the work was influencing the Joint Committee for Vaccination and Immunisation (JCVI).
- Aziz then introduced Hilary Pinnock who presented on remote consulting for people with asthma.
- Hilary Pinnock explained that remote consulting is an evolving situation and presented evidence focussing on acute care.
- Hilary then talked about the difficulties in assessing breathlessness in light of the COVID pandemic and how acute services are responding. Hilary also spoke about remote consultations in primary care showing a series of statistics and evidence from GPs.
- Hilary also spoke about her assessment of remote consultations for routine asthma reviews, through telephone conversations, citing that most reviews were shorter in length.
- Hilary explained the measures taken by GPs to reorganise to deliver safe care during the COVID-19 pandemic, describing the changes as a dramatic reorganisation.
- This was then followed by evidence showing the beneficial impact of the pandemic restrictions on transmissions of viruses which have lowered for people with asthma and how lessons can be learned as we emerge further from the pandemic.
- Hilary Pinnock then passed the presentation to David Weatherill for a patient perspective on remote consulting.
- David Weatherill talked about the anxieties of people with asthma because of COVID-19, however found that remote consultations were straightforward and worked well.
- David found that his experience of remote consultation worked well, but there were issues are proper diagnosis and testing to support diagnosis. However, he believed some of these issues could be overcome using smart technologies. David then passed back to Hilary.
- Hilary then discussed the GP experience of remote consultations – highlighting the positive and negatives raised by GPs.
- Technologies such as telephone, video-calling, online and SMS were used and explained by Hilary for people, who further detailed how these were used.
- Hilary then asked Noelle Morgan to discuss her role in supporting GPs to deliver supported self-management for people with asthma during the pandemic.
- Noelle highlighted a focus group that was organised with the support of AUKCAR to gain patient views. Noelle co-led the group, which had a range of different demographics and severity of asthma. The group discussed 5 different topic areas – where asthma information can be accessed, asthma action plans, asthma reviews, how people manage and understand their asthma, and remote consultations.
- Noelle talked about the outcome of the focus group, which produced 5 or 6 short videos for people with asthma to manage and support their asthma. These can be found on the Living For Asthma website and are accessible for all.
- Noelle then passed the presentation back to Hilary, who then further discussed remote reviews for asthma, including the practicalities of checking inhaler technique and utilising asthma action plans.
- Before ending her presentation, Hilary emphasised that remote consultations will not work for everyone and the new model of asthma, post-pandemic, must work for the patient.
- Hilary thanked members for listening and passed back to Monica to facilitate questions.

- Questions were posed to Aziz around asthma care and outcomes during the pandemic, misdiagnosis of asthma and how many people in Scotland live with severe asthma.
- Monica then asked the MSPs if their constituents had raised any concerns around remote consultations. Emma Harper answered first to say that as a registered practicing nurse working on vaccinations, she is aware of access to remote consultations being mixed from GPs working on the frontline. Emma's view from patients again showed that responses to remote was mixed and that it benefits some, not all asthma patients.
- Alexander Stewart said that Emma makes valid points about where Scotland is around remote consultations, particularly around the challenges for people with more than one condition.
- Mark Ruskell said that the responses he gets from constituents is that remote consultation should be supplementary and that there are other health areas that may not benefit form remote consultations.
- Monica then passed to Hilary to ask about costs associated and support provided to offer more remote consultations during the pandemic.
- Alexander thanked the speakers for their insights and passed over to Emma Harper to chair the remainder of the meeting.
- Emma also thanked the MSPs for attending and spoke of her joy at being a part of the group before passing over to Tom Fardon to discuss the Precision Sever Asthma Project and the Respiratory Care Action Plan (RCAP)

Precision - Severe Asthma Project

- Tom Fardon introduced himself to the CPG and spoke about his involvement as a lead in the development of the RCAP and also the Scotland lead for the Precision project. Precision focusses on severe asthma across the UK.
- The Precision works with the pharma industry – Astrazeneca – to identify patients, empower them and transform pathways for people with asthma.
- Tom pointed out the aims of Precision, which are 1) to accelerate appropriate referrals, 2) build capacity, 3) expand capacity and 4) improve access to better care.
- Tom explained why there is a Precision Scotland, which is mainly because of the differences between the Scottish and English health systems and showed the Scottish membership.
- The key priorities for Precision in 2021 were outlined by Tom. There are 6 in total.
- Tom responded to a question asked by Emma Harper about the numbers of people with severe asthma by saying there is insufficient data.
- The next part of the presentation was on OCS Stewardship – oral corticosteroids – and the work of the Precision programme in this area.
- Tom showed the 2022 areas of focus for Precision UK on patient identification and how to narrow down groups of patients to support their asthma.
- Tom then referred back to the 2021 key priorities and spoke about how successful each has been so far – completing 4 of the 6 priorities.
- Tom ended his presentation on Precision and moved on to the Respiratory Care Action Plan.

4. Respiratory Care Action Plan

- The RCAP published in March 2021, focusses on 5 lung diseases – asthma, COPD, IPF, sleep apnoea and bronchiectasis. Tom spoke briefly about why these were selected, mainly because they are 90-95% of all lung diseases in Scotland, adding in that Long COVID is an area of concern for the RCAP and pointed out the 5 priority area.

- Tom pointed out that work is being undertaken to identify the membership of what is to be called the Scottish Respiratory Advisory Committee (SRAC) to oversee the implementation of the RCAP and a patient group will also be created to feed into that committee. Dr Adam Hill will chair the SRAC.
- Tom also described the focus areas and also the timeline to meet the key priorities, showing the matrix of diseases and priorities.
- Tom thanked the CPG for listening and referred back to Emma Harper to chair any questions that he would be happy to answer.
- Emma Harper thanked Tom for his presentations and then raised a question from Mark Ruskell on funding for multi-year delivery of the RCAP. Tom responded to say that this is a priority for the Scottish Government and that there is funding ongoing for the RCAP.
- The next question came from Sara McArthur around the involvement of respiratory physiologists. Tom asked Sara to get in touch with him and he would be happy to discuss further.
- Emma read out the next question from Susi Shanks on how patient representatives can get involved in the RCAP and if PCD would be classed under bronchiectasis.
- Tom said that PCD would be under the bronchiectasis workstream and that details on patient involvement has not been formally set out yet and further updates can be provided.
- Mark Dodd then asked a question on early identification of people with severe asthma and how they can be untangled before referral or will they be referred to secondary care first, highlighting that some can be non-adherent or resistant.
- Tom responded to say that data can be challenging and accessing compliance can be challenging, showing the need for tools and pathways to be implemented to overcome the barriers of identifying people with severe asthma.
- Emma asked Tom if hub-models would be specific so people can learn about pathways and what hubs would look at.
- Tom said that this is something being addressed by Precision UK and who staffs these and where they sit, between primary and secondary care. Levels of experiences would be key according to Tom, who then referred to examples he knows but they can be dependent on the single experiences of staff.
- Katherine Byrne said that Chest Heart and Stroke Scotland is working with Asthma UK and British Lung Foundation and Alliance Scotland on the RCAP patient group.
- Joseph Carter then added to Katherine's point about the patient group to say that the work will begin in October and that Alliance's experience in this area would be very beneficial.
- Garry McDonald was then invited to ask the final question, before moving on to AOCB. Garry shared some views about insights from his colleagues in England that nobody fully understands what a hub will look like and that the first step would be to address what the outcomes will be first and referred back to Tom's presentation on the RCAP matrix.

AOCB

- Emma Harper thanked everyone and then asked Maureen Ward to raise her AOCB.
- Maureen Ward spoke on behalf of Action for Pulmonary Fibrosis to request that the CPG endorse calls from APF for the Scottish Medicine Consortium to lift restrictions for anti-fibrotic medicines for patients with IPF. *Full request can be found in appendix 1.*
- Emma agreed to speak with Alexander Stewart and Mark Ruskell on how to raise this and will speak with other colleagues in parliament such as Colin Smyth MSP.
- Emma asked Gareth Brown to close the meeting by notifying of the next meeting – 15/11/21

Appendix 1

Submission for the Cross-Party Group on Lung Health of the Scottish Parliament– meeting on 27 September 2021

This is a request to raise an item under Any Other Business. It is made by Action for Pulmonary Fibrosis (Scottish charity registration no. SC050992), represented by Steve Jones, Chair of Trustees. It is supported by Maureen Ward (Chair, Fife and Tayside Pulmonary Fibrosis Support Group) and Steve Chinn (Chair, Forth Valley Pulmonary Fibrosis Support Group). We are making this request now because September is Pulmonary Fibrosis Month in the UK and Europe.

This item concerns the treatments available to people diagnosed with Idiopathic Pulmonary Fibrosis (IPF) in Scotland. IPF is a chronic, progressive disease with several possible causes. It results in a build-up of scarring (fibrosis) in the lungs. The lungs become stiffer and smaller, and increasingly less able to transfer oxygen into the blood. It is estimated that c32500 people are living with IPF in the UK, and case numbers are growing (link to data review papers here and here). We estimate there are c3,000 people living with IPF and c1,500 with other types of progressive pulmonary fibrosis in Scotland.

Data on prognosis is unclear, but it is generally accepted that median (mid-point) survival is 2.5-3.5 years from diagnosis (link to data review papers here and here). The British Thoracic Society is establishing a Registry to provide clear data on incidence, prevalence, treatment effectiveness and survival. The 2021 BTS ILD Report is available to download here. ILD refers to Interstitial Lung Disease, the category term for fibrosing lung conditions.

We are asking the Group to consider endorsing the case for removing a restriction on the availability of the anti-fibrotic drugs nintedanib and pirfenidone. These drugs are used to slow the progression of fibrosis in the lungs. They are the only drugs used for this purpose.

At present, SMC advise clinicians to prescribe the anti-fibrotics with a predicted forced vital capacity (FVC) of 80% or below. FVC measures lung volume, and is a key indicator of lung function overall. This means that many hundreds of patients with an FVC over 80% are denied access to these treatments.

We would like to see this restriction removed, so that clinicians can prescribe the anti-fibrotics on diagnosis. This means not waiting for the deterioration in lung function that occurs as the fibrosis progresses.

There are four reasons supporting this proposal:

[1] The UK is the only country, anywhere in the world, that imposes this restriction.

[2] NICE plan to review the restriction for England and Wales (NICE Technology Appraisal Guidance TA 379: link to the decision paper available here).

[3] In June 2021, the Scottish Medicines Consortium (SMC) approved the use from diagnosis of one of the anti-fibrotics, nintedanib, for patients with forms of progressive pulmonary fibrosis other than IPF (SMC Detailed Advice Document here). IPF generally comes with a worse prognosis and shorter life expectancy than these other forms of the disease. On the face of it, this seems to be against common sense.

[4] Clinical trials show “no statistically significant differences between the effectiveness of nintedanib on slowing lung function decline in people with a percent predicted FVC of 50–80% and people with a percent predicted FVC of more than 80%” (NICE Guidance section 3.3, here).

We appreciate that SMC will examine cost-effectiveness in QALY terms, as well as clinical effectiveness.

We ask the Cross-Party Group to consider endorsing a call for SMC to be asked to review the restriction.

Thank you.