

PE1714/B

Chest Heart & Stroke Scotland submission of 1 August 2019

Thank you for the opportunity to contribute to the Committee's consideration of PE1714. We hope that the supplementary information provided below is of assistance.

Chest Heart & Stroke Scotland's focus is on ensuring that people affected by our long-term conditions have the best possible opportunity to live well. We therefore support the petitioners' ambitions to improve the diagnosis, treatment and care of people living with interstitial lung disease.

National Respiratory Action Plan

We are advised that interstitial lung disease (ILD) will be one of five key components of the Scottish Government's developing National Respiratory Action Plan (the others are COPD, Bronchiectasis, Sleep Apnoea, and Asthma). Early diagnosis and access to rehabilitation are likely to be strong threads in the national plan.

We have not had sight of the draft Action Plan, however the Committee may wish to seek an update from the Scottish Government as to whether it would go in some way to meeting the petitioners' proposals.

We welcome the Scottish Government's work to develop Scotland's first national respiratory plan. We have one of the worst records on lung health in Europe, with high prevalence and mortality rates, yet this has not previously been tackled at a national level. However progress on the respiratory plan has been very slow, and has provided no opportunity for patient engagement and involvement. We believe this has been a significant missed opportunity to take a patient-centred approach at a strategic level, and have written to the Minister for Public Health expressing those concerns.

Patients' experience of Idiopathic Pulmonary Fibrosis (IPF)

Action for Pulmonary Fibrosis is a UK charity founded in 2013 offering support for people with Idiopathic Pulmonary Fibrosis (IPF, the most prevalent interstitial lung disease). They currently have three peer support groups in Scotland (in Aberdeen, Kirkcaldy and Paisley).

The charity recently conducted a survey of people living with IPF, revealing high levels of misdiagnosis at a UK level. The report, *Giving Patients a Voice* is available at <https://www.actionpulmonaryfibrosis.org/>. The key findings are listed below:

- More than a third of respondents to the survey (35%) had been misdiagnosed, most commonly by general practitioners who commonly assume the patient

has asthma, chronic obstructive pulmonary disease (COPD) or cardiac problems.

- Over half (54%) of IPF patients wait more than six months to be diagnosed. One fifth of respondents (20%) took more than two years to be diagnosed correctly. Life expectancy is only 3-4 years.
- IPF kills more people each year than leukaemia, brain or stomach cancer yet receives only a small amount of research funding – making it one of Britain's 'hidden killers'
- Specialist nurses: Almost a third of patients (29%) lack access to a specialist nurse. Those who have access do not always receive the full level of support they need.
- Pulmonary rehabilitation: Only 53% of IPF patients have completed a course of pulmonary rehabilitation (exercise and education classes) and only 14% receive pulmonary rehabilitation tailored to the needs of IPF patients.
- Feeling well supported: Only 63% of patients feel well supported in managing their IPF, a drop from 76% in the last survey in 2015

Training for the medical profession

Scotland has three specialist ILD nurses, who are based in NHS Lothian, NHS Greater Glasgow & Clyde, and NHS Grampian. However it is important that wider non-specialists have sufficient knowledge of respiratory conditions. As the petitioners describe, levels of awareness of ILD are very low among patients, and health professionals may have limited case experience given the number of rare diseases covered by the umbrella term.

Chest Heart & Stroke Scotland recently launched a free e-learning resource called 'RESPe' – Respiratory Education to Support Professionals through eLearning¹. This is aimed at health and social care professionals who are not respiratory specialists, and provides a basic knowledge of common respiratory conditions. RESPe aims to improve patient/client care by increasing the knowledge and skills of any member of health and social care staff working with people living with respiratory conditions in health, social or private care settings.

RESPe includes an introduction to ILD, and a comprehensive section on Idiopathic Pulmonary Fibrosis (IPF), the most prevalent ILD.

Intended users are:

- Staff and students who are new to working with respiratory patients/clients.
- Staff who wish to refresh or extend existing respiratory knowledge.

¹ <https://www.chss.org.uk/news/respe-respiratory-education-to-support-professionals-through-elearning/>

- Staff who have a mixed caseload which includes some respiratory patients/clients.
- Staff working in the private sector who have limited access to specific respiratory training.

Funded by the Scottish Government, RESPe was developed in collaboration with NHS Scotland respiratory clinicians, and the University of Edinburgh Digital Learning Applications & Media team.

Support for people living with ILD

As the petitioners describe, respiratory disease has a significant impact on every aspect of someone's life. The most common symptoms – breathlessness and fatigue – are debilitating and frightening. Anxiety and ongoing poor health can lead to mental health problems and isolation.

Last year we carried out a national survey² of people's lived experience of long-term health conditions. Half of respondents living with chest conditions told us their confidence was affected, causing them anxiety and stress. If left undiagnosed or untreated, anxiety and depression can worsen people's physical symptoms and affect their use of medication. Over half told us their condition limits their ability to get out, with a corresponding loss of independence. Sixty-five percent said their ability to be physically active is affected.

Pulmonary rehabilitation (PR) is mentioned by the petitioners as important in maintaining quality of life. PR is a treatment proven to be both clinically and cost-effective, supporting people to self-manage their conditions. It combines physical exercise with education, advice and support for people, improving fitness and strength, and supporting learning to help control symptoms like breathlessness. Through regular group activities, it builds people's confidence in their ability to get active and live as independently as they can.

However our report on the Right to Pulmonary Rehab³ highlights that the provision of PR is hugely variable across Health Boards, creating a difference in the support available to people living with chest conditions. The capacity of programmes does not meet the level of need, referral numbers are sometimes very low, and waiting times long.

The NICE guidance on IPF⁴ recommends that patients should be regularly assessed for PR. We believe that awareness of the benefits of PR are low amongst both respiratory patients and health professionals. For people living with symptoms such as breathlessness and fatigue, being active can seem counter-intuitive. Health

² <https://www.chss.org.uk/documents/2018/10/one-in-five-report-pdf.pdf>

³ <https://www.chss.org.uk/wp-content/uploads/Report-Pulmonary-Rehab.pdf>

⁴ <https://www.nice.org.uk/guidance/cg163>

Boards advised us last year in response to FOI requests about their provision of PR that they were providing PR for patients with ILD, however we do not have data on whether that matches the level of need.