



Briefing for the Public Petitions Committee

Petition Number: [PE1714](#)

Main Petitioner: James McLachlan, Ivy Dodds and Jean Watson

Subject: Interstitial Lung Disease and Home Management

Calls on the Parliament to urge the Scottish Government to provide funding to raise awareness of Interstitial Lung Disease and home management.

Background

Interstitial Lung Disease (ILD) is a term which encompasses a number of different conditions that result in scarring (fibrosis) and stiffening of the interstitium in the lungs. The interstitium is a lace-like network of tissue that supports the alveoli (air sacs). Fibrosis causes the lungs to thicken and scar and this impedes the transfer of oxygen. As a result, the main symptom of ILD is shortness of breath, but people may also experience a cough, tiredness and weight loss.

There are many conditions which cause ILD but the main causes include idiopathic pulmonary fibrosis and sarcoidosis.

Epidemiology

There is no centrally recorded data which estimates the number of people in Scotland who have ILD. However, the British Thoracic Society operates a UK registry for ILD which, as noted above, is sub-divided into two of the main causes; Idiopathic Pulmonary Fibrosis (IPF) and Sarcoidosis. Data from the most recent [registry report](#) and the [British Lung Foundation](#) sets out the following key statistics for each condition:

Idiopathic Pulmonary Fibrosis

- The prevalence rate of IPF in the UK is estimated to be 50 per 100,000 people, with the highest rates in Northern Ireland, North West England, Scotland and Wales.
- There are estimated to be over 30,000 people in the UK living with IPF and annually there are more than 5,000 new cases.

- In 2012, over 5,000 people in the UK died of IPF. This is around 1% of all UK deaths over a year and represents 4.6% of all UK deaths from lung disease.
- The reported median survival in IPF is 3 years from diagnosis.
- IPF has a poorer prognosis than many cancers including colon, breast or ovary. Only 20% of IPF patients are reported to survive to 5 years post-diagnosis.

Sarcoidosis

- There are estimated to be over 100,000 people in the UK living with sarcoidosis and around 4,500 new diagnosis each year.
- Patients with pulmonary sarcoidosis account for up to one third of ILD patients in specialist respiratory clinics.
- Around 170 people in the UK died from sarcoidosis in 2012.
- Prevalence rates for sarcoidosis are higher in Northern Ireland, Scotland and London. This is thought to be down to a genetic predisposition to sarcoidosis.

Treatment

Treatment for ILD includes steroids and - for those with IPF - medicines that slow its progression (pirfenidone and nintedanib). Other treatments include pulmonary rehabilitation and oxygen therapy. Sufferers may also need practical support to carry out the activities of daily living.

There are no Scottish clinical guidelines for ILD or any of its main causes. However, the National Institute for health and Care Excellence (NICE) in England produced [guidance on Idiopathic Pulmonary Fibrosis](#). In the absence of Scottish guidelines, Scottish clinicians would be expected to pay heed to guidance produced by NICE.

NICE also produced [quality standards for IPF](#). The standards set out what people with IPF should expect from their care. There are no equivalent standards in Scotland. However, the National Advisory Group and the respiratory Managed Clinical Networks (see below) have local protocols and guidelines which may also be of relevance in the treatment of ILD.

Scottish Government Action

The Scottish Government established the [National Advisory Group for Respiratory Managed Clinical Networks](#) (NAG). The aim of the NAG is to foster respiratory health, improve the quality of care for patients with respiratory disease throughout Scotland and to encourage the implementation of good practice through the 14 local Managed Clinical Networks (MCN) which operate

in each NHS board area. MCNs are coordinated networks of professionals involved in providing care across a region.

The Scottish Government is also at the very early stages of creating a task group which will develop a respiratory plan for Scotland. There are no details yet on the terms of reference for the group or what the plan will cover.

Scottish Parliament Action

The Scottish Parliament has not undertaken any work specifically on ILD.

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SPICe Research
10 January 2019

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