

PE1714/D:

Scottish Government submission of 12 August 2019

I refer to your e-mail of 9 July 2019 to Carole Finnigan - Committee Liaison Officer seeking the Scottish Government's view on the action called for in the petition, particularly with regard to the prevalence of the condition, the awareness of the condition, training for the medical profession and support for people who have the condition.

Policy context

It may be helpful to first set out the context of policy development underway to improve the way services are delivered for people living with respiratory conditions, including Interstitial Lung Disease (ILD).

As you may be aware, we are currently in the process of developing the Scottish Respiratory Care Action Plan, which we aim to publish for consultation later in 2019.

The aim of the Plan is to provide a framework for action by Health Boards and set out the Government's expectations of the NHS in Scotland to tackle respiratory conditions no matter where patients live and whatever their circumstances.

The Plan will operate alongside the many programmes of work that are already underway to improve care and outcomes for people with all types of respiratory conditions.

For example, respiratory is one of the speciality areas taking part in the Scottish Access Collaborative (SAC) programme, which is looking at ways people can receive timely and accessible care.

The SAC, launched in November 2017 by the Cabinet for Health and Sport, is working to sustainably balance demand and capacity and establish effective and efficient interfaces between primary and secondary care.

The Scottish Collaborative Access Respiratory Specialty Group brings together clinical, patient, managerial and planning perspectives with the aim to collaboratively understand, address, and reduce the current waiting time on respiratory pathways, improving patient experience and ultimately suggesting improvements for the services provided in the future.

The petitioners raised the point of symptoms of ILD: the Group is already working to identify the most common or pressing symptoms before mapping some common pathways, highlighting areas of best practice, and flagging areas with the most potential for improvement.

Detailed work on the group can be found at <https://learn.nes.nhs.scot/6270/scottish-government-health-and-social-care-resources/scottish-access-collaborative-making->

Background and prevalence

Interstitial lung diseases (ILDs) are a large group of conditions which cause inflammation and/or scarring (fibrosis) within the lungs, and are often referred to as “lung fibrosis”. Some ILDs have a known cause, such as occupational lung disease (e.g. asbestosis), but in many cases the cause is unknown. Although there are more than 150 individual types of ILD, many are rare, the most common are Idiopathic Pulmonary Fibrosis (IPF) and Sarcoidosis.

Idiopathic Pulmonary Fibrosis (the most prevalent type of ILD) is believed to have a prevalence of around 15-25 per 100,000 (NICE 2013). There are more than 5,000 new cases of IPF in the UK per year (NICE 2013). The median survival for people with IPF is 3 years from diagnosis. Survival rate at 5 years post diagnosis is around 20% (NICE 2013).

Awareness of the condition

There are a range of tools and communications used to reach the widest possible audience and raise awareness of a wide range of different types of illnesses, infections, injuries and disorders.

NHS inform (www.nhsinform.scot) is Scotland's dedicated resource offering up-to-date facts on health, services and campaigns. It also has a wealth of information available online, over the telephone or via webchat. NHS Inform also signposts to relevant charities websites, where further information may be obtained.

NHS Inform contains a section focused on ILD with detailed information about the symptoms, diagnosis, and treatment of the condition.

Charities play a very important role in raising awareness of specific conditions. For example, The British Lung Foundation has a variety of information leaflets, including one on IPF, that are available on line and can be ordered by healthcare professions. Recently, in June 2019, the Scottish Parliament held a debate, “Love Your Lungs Week” and supported the British Lung Foundation’s online breath test campaign, which seeks to raise awareness of the early warning signs of lung disease.

There are also national campaigns that raise more general health awareness messages, such as the recent one encouraging people to use their community pharmacist as their first point of access for care and advice.

Training for the medical profession

It is crucial for healthcare professionals, such as GPs, to be aware of condition specific education materials and relevant guidelines to aid them in supporting their patients and to enable timely diagnostic investigations to take place. We understand the considerable challenge this presents our NHS on the frontline and therefore earlier this year the Scottish Government published a Digital Health and Care Strategy about

how care for people in Scotland can be enhanced and transformed through the use of digital technology.

At the centre of this is ensuring that technology supports healthcare professionals and people to access and use information and services in order to make timely and informed decisions about their care, as well as provide flexibility around communications to better meet people's individual needs. Examples of this are already in operation, such as the Attend Anywhere app (<https://www.digihealthcare.scot/home/case-studies/in-the-workplace/attend-anywhere-offers-video-consultation/>).

As we move forward, the use of technology will provide a positive contribution both in terms of advancing person-centred care, quality improvement and patient safety outcomes, in all areas of healthcare including for respiratory conditions.

NHS Education for Scotland (NES) has a key role in co-ordinating recruitment to, and overseeing, the quality of postgraduate medical training for both GPs and hospital specialists. The training curricula are written by Medical Royal Colleges and approved by the General Medical Council (GMC), who considers advice from a wide range of stakeholders, including NES. These are subject to regular review and updating, and the training is delivered by territorial NHS Boards in clinical placement settings, also approved by the GMC.

In addition to the above, and specifically for respiratory conditions, the Scottish Government has provided funding of £112,000 to Chest Heart and Stroke Scotland (CHSS) to support the development of an online learning resource - RESPe (<http://www.respelearning.scot/>). This is a free, interactive e-learning resource which provides a basic knowledge of respiratory conditions, including ILD. The aim of the resource is 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.

Home Care and Support

The Scottish Government is committed to improving the quality of care in Scotland and wants to ensure that everyone who requires care has access to the highest standards of care in every setting, including their own home. Clearly the Scottish Government has overall responsibility for health and social care policy in Scotland. However, it is the responsibility of local health and social care partnerships to determine what level of services are required to meet local needs and to arrange an appropriate range of services to meet these needs. This must be done with engagement with their local communities.

We recognise that social care support is an area facing a number of challenges, both in terms of current provision and meeting the likely levels of need in the future.

The integration of health and social care in Scotland has created new opportunities for collaboration with people, professionals and communities to re-design what supports and services look like and how they are delivered. This is both to ensure people and

communities are supported in the way that is right for them and experience high quality care into the future, and that Scotland's models of care are sustainable.

The Scottish Government expects Health and Social Care Partnerships to make every effort to ensure that appropriate care and support is provided locally. We recognise that redesigning services can be challenging. Integration Authorities are aiming to deliver better care and support for people by making better use of the significant resources we invest in health and social care services. They are doing this through a strategic commissioning approach which requires partnerships to work with local communities, and listen to their views and opinions as they seek to improve the quality and sustainability of services.

We will continue to work with relevant statutory bodies and third sector partners to ensure that the issues raised by the petitioners are addressed across all sectors including education, health and social care.