

# 2017 Pulmonary Rehabilitation Survey

By Chest Heart & Stroke Scotland in partnership with the  
Scottish Pulmonary Rehabilitation Action Group



## Chest Heart & Stroke Scotland's Call to Action



### What is Pulmonary Rehabilitation?

Pulmonary Rehabilitation (PR) combines physical exercise with education, advice and support for people living with lung disease. It helps by improving fitness and strength as well as supporting learning to help control symptoms such as breathlessness. Through regular group activities, PR builds people's confidence in their ability to get active, live as independently as they can, and helps their overall health and wellbeing.

Referrals are usually made by a GP or other health professional, and the programmes last for a fixed period of weeks. Health guidance recommends that PR should be provided by the NHS as a treatment option for people living with long-term lung conditions.

### Why is Pulmonary Rehabilitation important?

PR is proven to improve the lives of people living with Chronic Obstructive Pulmonary Disease (COPD) and other lung conditions such as pulmonary fibrosis, stable asthma and bronchiectasis.

People living with a long-term lung conditions are amongst the biggest users of health services in Scotland, with over 129,000 people diagnosed with COPD. There are over 19,000 hospital admissions each year due to COPD, and 129,300 beds days accountable to the disease.

By helping people stay well and self-manage their conditions, PR reduces the number of hospital admissions and time spent in hospital, saving the NHS money.

### The Survey of Pulmonary Rehabilitation

The survey was undertaken by Chest Heart & Stroke Scotland in 2016-17 on behalf of the Scottish Pulmonary Rehabilitation Action Group (SPRAG), a national group of health professionals which promotes the value of PR.

Until now there has been little data available about the provision of PR services in Scotland, including whether they meet clinical guidelines. There has been no opportunity for comparison by health professionals or patients which could highlight variations or areas of effective practice. The survey provides information on 11 out of 14 regional health boards' PR services, and highlights the key problems:

- there aren't enough places available on PR for everyone that needs it,
- there aren't enough referrals being made by health professionals, and
- people struggle to complete their courses of PR.

Despite the evidence showing that PR is an essential part of helping people manage their lung disease, PR is not available in all health board areas in Scotland. Programmes that do exist vary in the numbers of people they can help, and what they provide. There are UK standards in place for how PR should be delivered, but some areas struggle to meet these.

## Key findings

- Pulmonary rehabilitation programmes vary widely in format, capacity and delivery. NHS Borders has no pulmonary rehabilitation service.
- An estimated 69,000 people would benefit from PR, but there are only 9,000 places per year available.
- Many people who would benefit from rehabilitation are not being referred by their GPs, and more research is needed into the reasons why.
- Waiting times to begin rehabilitation range from 2 to 26 weeks, although most start within the recommended 3 months. Following an exacerbation of COPD (where people become unwell again) the recommended referral to rehabilitation is within 1 month, but only half of services can meet this target.
- Many people referred to rehabilitation are not completing their programme, which is a reflection of the physical and practical challenges people face when living with chronic lung disease.
- Only one PR programme in Scotland has input from a clinical psychologist, despite the well-documented link between anxiety, depression and long-term respiratory conditions.
- Developing exercise plans for people after completing their rehabilitation programmes encourages continued exercise, but only half of rehabilitation programmes provide plans.
- The benefits of rehabilitation can be lost within 6-12 months if people do not remain physically active. Although all rehabilitation services can refer or suggest options for ongoing support, only two-thirds of programmes include monitoring of longer-term outcomes.

## What are the challenges?

Despite the effectiveness of pulmonary rehabilitation having been proven, a low percentage of the people who can benefit from PR actually receive it. In addition to the need for more resources to better fund PR, there are a number of other challenges:

- People are often not being referred to PR services by health professionals. This may be due partly to a lack of understanding and awareness about the benefits of PR.
- It can be difficult for people to attend a course of PR. Many people with long-term lung conditions are anxious about exercise because they are concerned about worsening their breathlessness and fatigue. They need support and encouragement to attend, and to be told about the benefits of PR.
- The numbers of people completing PR programmes can be low which is partly because of the challenges they face, particularly with changes to their health over weeks or months.
- People living with symptoms like breathlessness can find it hard to get to venues, struggle to use public transport, or sometimes even walk across a car park or down a hospital corridor. According to this survey, just over a third of PR services are unable to offer any transport, and those that can

have limited options available.

- People with worse lung disease can be too frail to attend PR. It's important that they receive earlier referrals from their health professionals while their health is better. There also need to be ways of delivering PR to people who can't attend a class, for example at home.

## Recommendations

1. Integrated Joint Boards need to increase investment in PR to meet local need. This will deliver savings through reduced hospital readmissions.
2. Awareness needs to be raised about the benefits of PR among health and social-care professionals and the public. This would improve rates of referral, participation, and completion of PR programmes.
3. Steps need to be taken to actively address the barriers which stop people:
  - i) being referred to PR programmes, and
  - ii) participating.
4. PR services need to support people who complete the programme to move into community exercise and support, so they can maintain the benefits they've gained from PR.
5. There needs to be better national data available about how PR is provided across the country. This would benefit service users and providers by showing where areas of good practice are which would help drive improvement.

## Chest Heart & Stroke Scotland's Call to Action

1. By 2021 every Integrated Joint Board should meet a target of doubling the number of places available on PR programmes, with waiting times kept within the recommended timescales.
2. Every Integrated Joint Board should have an action plan setting out how it will actively address the barriers which stop people being referred to PR programmes, and which stop them participating. This should include awareness raising about PR amongst health professionals and the public, and the local delivery of a pathway into ongoing community based physical activity.
3. The Scottish Government should ensure that the developing Lung Health Quality Improvement Plan for Scotland includes clear requirements for the provision of Pulmonary Rehabilitation for all those who would benefit.
4. NHS Scotland should establish a national dataset about PR provision which would enable benchmarking and inform service development and improvement.

To read the full report, or to join the CHSS campaign for more support for people with lung disease see [www.chss.org.uk/lungrehab](http://www.chss.org.uk/lungrehab)