International Primary Care IPCRG Respiratory Group

POSITION PAPER

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Pulmonary Rehabilitation (PR) helps people breathe better, feel good, and do more: Why you should invest in PR for your population

This paper demonstrates why healthcare systems that develop their capability to deliver easily accessible PR to urban and rural communities can improve health, social, and economic outcomes.

Case for Change

An estimated 1 in 10 adults live with chronic breathlessness.[1] Cardiac or respiratory disease causes two thirds of breathlessness.[1] More than 1 billion people globally suffer from a chronic lung condition.[2]

People whose lives are limited by chronic breathlessness live in every country and in every socioeconomic group, but those who are poor, old, or physically weak are particularly susceptible. Breathlessness is often frightening for the individual. It limits day-to-day activities including participation in work, domestic activities, and caring roles. Living with an illness that causes breathlessness can also ruin and diminish the lives of whole families. It presents a considerable challenge to traditional healthcare services because it is often misdiagnosed or underdiagnosed, and inappropriately treated.[1] Yet there is an effective intervention. Pulmonary Rehabilitation (PR) supports people in regaining their lives:

> *"Now I can go back to school."* Ugandan school girl with post-primary tuberculosis in an IPCRG-supported study.

> *"When I asked my patient what difference the PR programme had made, he said now he could walk to the market, but most importantly, to prayer again."* Dr Rowshan Alam, Bangladesh

> *"Even walking a few metres away, I would come back very breathless as if I have been running. But now I am even thinking of resuming attending to my kiosk since I can walk, stand for long, pain has reduced, and less dependent to others."* 56 year-old woman, Uganda, FRESH AIR study.

PR is a non-pharmacologic therapy combining tailored exercise and education. It is recognised as the most effective therapeutic strategy to reduce shortness of breath and improve health status and quality of life.[3] However, because the positive patient outcomes achieved by PR are unfamiliar to many clinicians, it is often undervalued and underused. At present, most people who would benefit are unable to access PR:

> *"Until you (group PR facilitators) came along, my life was purgatory. I didn't know what was going on or how to cope. Now I know what to do when I'm breathless. I no longer go into a blind panic. I am in control of my breathing."* Testimonial of PR clinic attendee, Whittington Hospital Trust, London, UK.

The impact of breathlessness: chronic obstructive pulmonary disease (COPD)

Chronic breathlessness affects up to 30% of older people and 10% of younger people, therefore affecting those who are economically and socially active.[4] The following facts highlight the burden of COPD, which is one of the more common causes of chronic breathlessness seen in primary care.

- COPD is now the third leading cause of death worldwide, accounting for an estimated 3 million deaths – 5% of all deaths – in 2015.[5-7]
- More than 90% of COPD deaths occur in low and middle income countries (LMICs).[7]
- The burden of COPD is growing in LMICs due to higher smoking rates, household and outdoor air pollution, and extended life expectancy;[7] and is increasing among socially and economically active populations (> 30 years).[8]
- Although LMIC prevalence data are often inadequate, estimates are higher than in high-income countries. A recent study in rural Uganda found that the prevalence of spirometry-defined COPD in people older than 30 years was 16%, and was especially high (39%) in those aged 30 to 39 years.[9]
- Much of the burden of COPD arises from psychosocial impacts of chronic breathlessness and cough that impair physical activity and result in isolation, anxiety, inactivity, and a spiral of decline. This begins in early mild disease. PR can address and even reverse these negative psychosocial effects.[10]

Cost burden of chronic lung disease

Breathlessness costs countries billions of dollars each year in lost productivity and increased healthcare expenses.[8]

The Organisation for Economic Cooperation and Development (OECD) has reported the impact that chronic lung diseases have within Europe on both direct health service costs and indirect costs of lost production (Table 1). The OECD

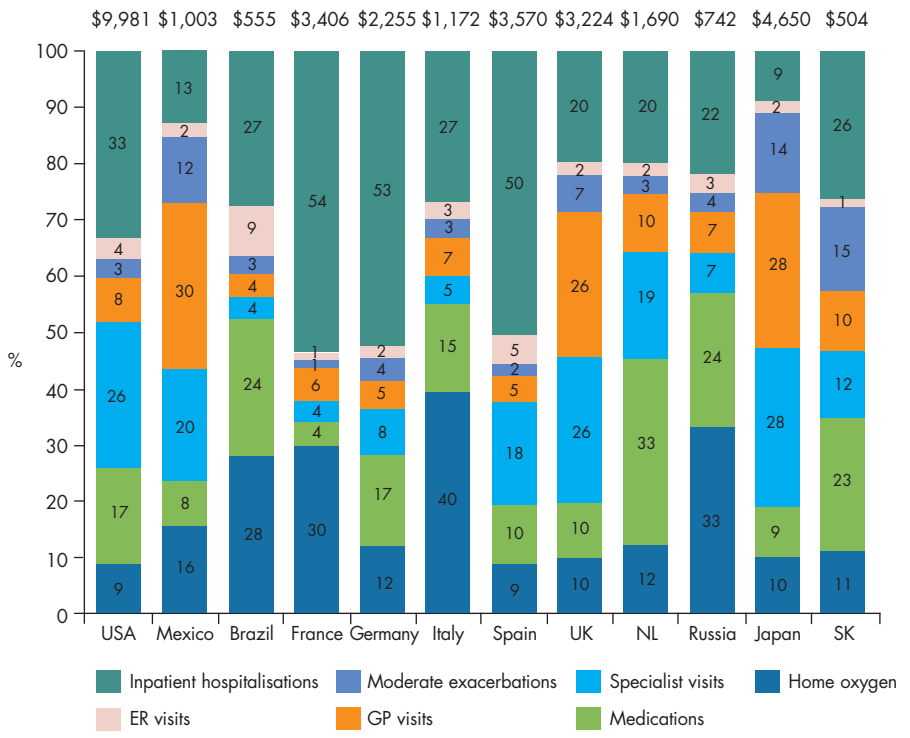
Table 1 OECD study into the cost of lung diseases in Europe[11]

	Direct costs# € bn	Indirect costs¶ € bn	Monetised value of DALYs lost € bn	Total costs € bn
COPD	23.3	25.1	93.0	141.4
Asthma	19.5	14. 4	38.3	72.2
Lung cancer	3.35	NA	103.0	106.4
TB	0.54+	+	5.37	5.9
OSAS	5.2	1.9	NA	7.1
Cystic fibrosis	0.6	NA	NA	0.6
Pneumonia/ALRI	2.5	NA	43.5	46.0
Total	55.0	41.4	283.2	379.6

DALY: disability-adjusted life year; COPD: chronic obstructive pulmonary disease; TB: tuberculosis; OSAS: obstructive sleep apnoea syndrome; ALRI: acute lower respiratory infections; NA: not available. # primary care, hospital outpatient and inpatient care, drugs and oxygen; ¶ lost production including work absence and early retirement; + indirect costs included with direct costs.

▶

Figure 1 Direct and indirect costs associated with COPD[11]



calculated that the annualised costs of COPD in the 28 EU countries for 2011 were €23.3 billion for direct costs and €25 billion for indirect costs.[11] However, these costs likely underestimate the true lifetime costs for chronic lung diseases.

The allocation of costs as direct and indirect differs according to country and setting (Figure 1), however, secondary healthcare costs (staffed hospital beds) usually dominate as the main contributor to direct costs.[12]

Annualised costs distort the true burden of disease. They highlight short-lived, high-cost, high-mortality diseases, such as lung cancer, and overlook the lifetime costs of chronic diseases, such as COPD, where the total treatment and costs are spread over many years after diagnosis and are likely to be 20 to 30 times the annual cost.[11]

PR offers effective management of breathlessness

Fatigue and breathlessness with little exertion are common symptoms of chronic heart failure (CHF) and COPD and can be very frightening for people with these conditions and their families or carers.[13] Normal daily activities such as walking up a short flight of stairs or up a slope, or carrying a heavy bag are difficult; going to the market becomes impossible.[13] As a result, people may avoid activities that make them breathless, leading to physical deconditioning, demotivation, and potentially, social isolation.[13] Figure 2 shows the spiral of decline associated with this deconditioning (grey) and the reversal of this process (green) achieved through PR.

Evidence-based smoking cessation is the most effective and cost-effective treatment for people with COPD who smoke.[14] Pharmacologic treatment is also effective in reducing breathlessness.[3] However, neither are currently available everywhere, and they do not reverse or cure lung damage or equip individuals with resources to manage their condition for a more productive and better quality of life. PR is best positioned after having initiated tobacco dependence treatment, where relevant, and having optimised pharmacologic therapies.[3]

Early identification of people who are experiencing difficulties due to breathlessness and offering PR have been shown to be effective in helping them maintain their level of activity.[15]

PR is a highly-evidenced[15] treatment that, when used alone or alongside pharmacotherapy, can make a significant difference to how individuals live with their illness and cope with the distressing symptoms of breathlessness.[15,17] It is fundamental to, and should be integrated into, the overall care of people experiencing breathlessness.[3]

In some low income countries it may be the only intervention available (see www.ipcrg.org/freshair).

Figure 3[16] illustrates the relatively low costs of PR compared with other interventions for managing breathlessness, thus representing good value for money. PR has also been shown to reduce the use of expensive services such as hospital inpatient care.[18] It can be delivered safely in the community or home setting, outside of hospital, using readily available resources.[3,13,15] Despite its proven clinical and cost-effectiveness, PR is widely underused.[19]

PR is a structured programme tailored to the individual to reduce their breathlessness and improve their quality of life (including their fear of breathlessness), exercise capacity, and ability to participate in daily life. It is an exercise-based programme accompanied by self-management education to help people live better with chronic lung disease.

Although exercise training is an essential component to any PR programme,[20] the educational elements that teach people about the cause of their breathlessness, practical coping skills, and secondary and tertiary prevention should not be overlooked.[11] The structure, setting and detail of how PR is delivered varies greatly from country to country.[21] **The IPCRG Desktop Helper describes how a PR programme can be structured** www.ipcrg.org/PR

Who benefits?

PR is beneficial for individuals whose activity has been limited by their breathlessness.[3,13] Typically, people with COPD are referred for

Figure 2 Reversing the spiral of decline & deconditioning

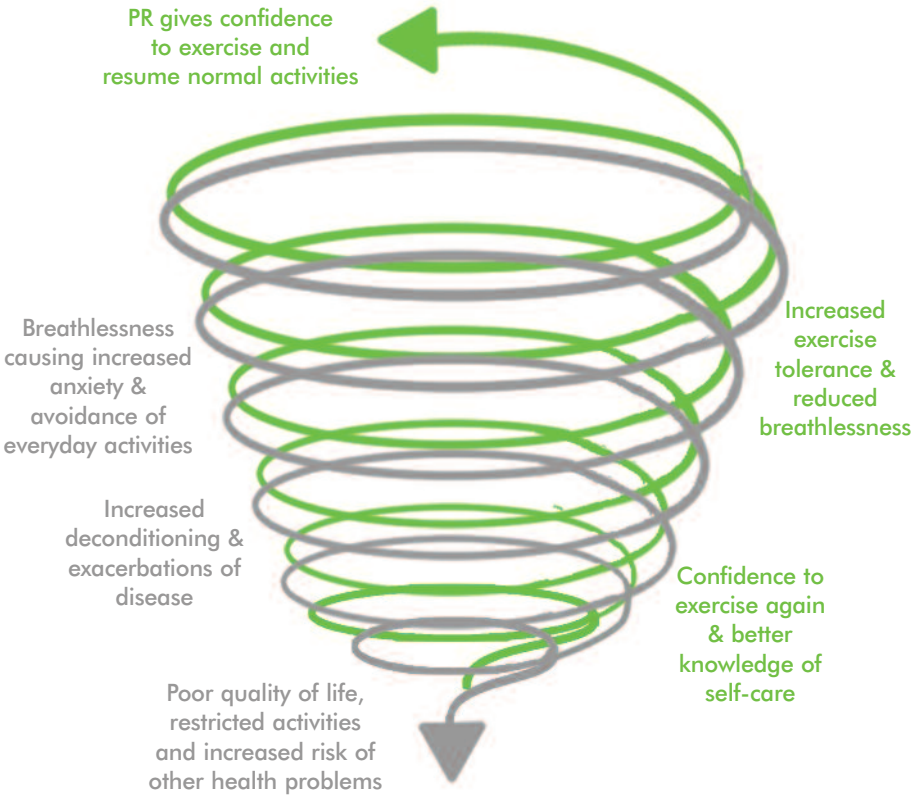
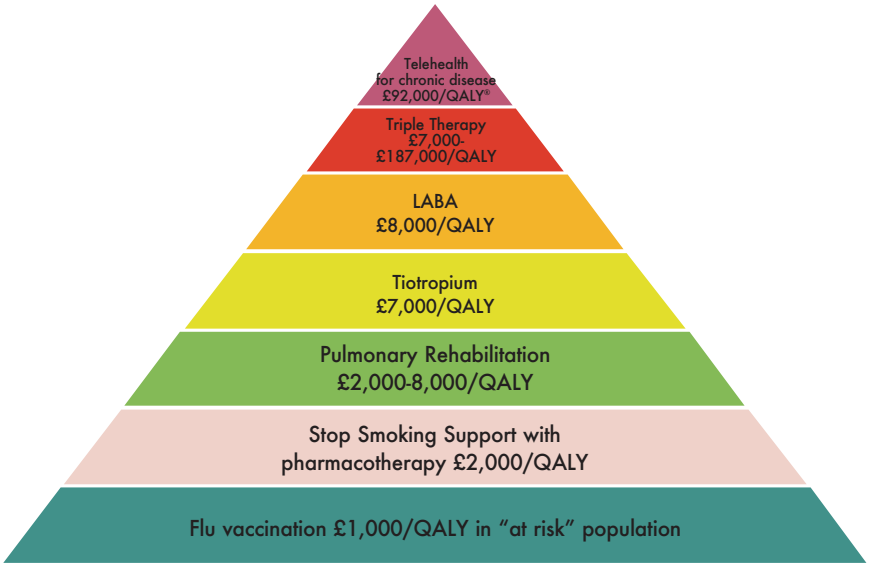


Figure 3 London Respiratory Network COPD value pyramid[16]



PR, however, studies have shown that some people with heart failure,[13,15] asthma, and other long-term lung diseases such as bronchiectasis or idiopathic pulmonary fibrosis (IPF) can also benefit.[15] We recommend that anyone assessed with a Medical Research Council (MRC) Breathlessness Scale grade 2 or above would benefit from PR (and physical activities).[20] Some guidelines suggest patients with an MRC Breathlessness Scale grade 3 and above would benefit most.[22] In reality, access to PR depends on burden of disease, available resources, and local referral thresholds.

Tangible benefits for people

- ✓ Relieves breathlessness
- ✓ Reduces tiredness
- ✓ Prevents deconditioning and disability
- ✓ Improves quality of life
- ✓ Improves mood and their sense of control over their condition

PR can relieve breathlessness and tiredness, improve emotional function, increase a sense of control over the condition,[23,24] improved quality of life, and can reduce the risk of premature death.[13] PR following hospital admission has also been shown to reduce the risk of subsequent admissions and mortality, although results vary considerably depending on how well the services are able to replicate the set-up used in research studies.[25,26]

This position paper focuses on community-based, rather than hospital-based interventions, as the IPCRG believes that to achieve fair coverage and access to care, services should go to where the people are. In some cases, hospital provides the most accessible location, but community or homebased PR is as effective.[15] ***The choice of location should be governed by accessibility, not type of setting, because the facilities required can be provided in most settings.***

Where can rehabilitation be provided?

In the past, PR has focused on programmes requiring equipment, knowledge, and skills that are in short supply and available mainly in hospital settings.[15] However, there is growing recognition and experience showing that simpler interventions delivered in community settings can work just as well. Walking to improve exercise capacity, for example, is relatively easy to prescribe, cheap, can be done anywhere, and more important, is a meaningful activity for people to engage in. Strength exercises can be done with everyday items such as bottles filled with sand to the required weight. **An important role of PR is to give people the belief, confidence, and physical capability to do these simple interventions on their own or with limited support, and to develop a habit that will continue after they have been discharged from the programme.**[3,15]

The World Health Organization argues that community-based rehabilitation (CBR) schemes are as effective as, and more accessible, than institutional-based schemes.[27] CBR schemes enable training for health workers to provide rehabilitation to the people in their communities so that they retain independence and remain productive community members.[28] They are able to use the social capital of the individuals' families and communities to achieve measurable clinical results.[19]

PR is well suited to community-based delivery as exercises in local settings support the individual's ability to function in their familiar daily activities,[15] such as walking, going up and down hills or steps, getting out of a chair, or even washing and dressing themselves. PR can be, and needs to be, continued at home during and following the programme to meet the exercise prescription that will deliver the evidence-based outcomes.

Through training CBR workers, rehabilitation professionals can spread rehabilitation services more widely and directly involve local communities. Developing a multidisciplinary rehabilitation workforce appropriate to the country context enables payers to ensure rehabilitation concepts such as breathlessness assessment, exercise using FITT (frequency, intensity, time, and type) principles, and structured education (see IPCRG Desktop Helper) are promoted sustainably across the health workforce. This approach to planning and building a comprehensive rehabilitation service delivery model enables health economies to progressively achieve equitable access to quality services for all the population, including those in rural and remote areas. In this way, self-management education can be integrated into local delivery systems in primary care, which can promote sustained benefit from continued training after the programme has finished.[3]

We call for governments and health-care organisations to develop their capability to deliver PR within easily accessible settings in both urban and rural communities, and with the same priority as medical prescriptions.

The value of accessible PR and current variation in access

Pulmonary Rehabilitation is cost-effective and yields good value when compared to other interventions for people with COPD.[16,29] PR is most effective when complementary interventions are optimised. It may also encourage participants' uptake of cost-effective interventions such as pneumococcal vaccination, tobacco dependence treatment, and correct use of inhaled therapy, particularly if supported by on-the-spot personal advice on breathing techniques, and the psychological management of fear of breathlessness.[30,31] It has a favourable impact on health outcomes, quality of life, and direct costs.[32]

Substantial benefits of physical activity for breathlessness

- ✓ Benefits to the individual: better able to live with their condition, slows the decline in functional impairment, reduces mortality, able to live more independently
- ✓ Benefits to the family: individuals are more active participants in family duties and activities
- ✓ Benefits to the community: people stay active and can work longer
- ✓ Benefits to the healthcare payers: reduction in the use of the most expensive healthcare resources such as staffed hospital beds, which reduces direct care costs

Affordability depends on local organisation, staffing, setting (ambulatory/outpatient/inpatient), type of programme (rolling/cohort/semi-rolling), and number of sessions offered (at least twice weekly 1 to 2 hour sessions, each including structured exercise and education, for 6 to 8 weeks). (See IPCRG desktop helper). Maximal benefit also depends on systematic feedback from the providers of PR to the referrer, based on their observations and support of the individual during 20 to 30 hours of direct care.

Despite being a widely recommended standard of care in guidelines for the management of chronic lung diseases such as COPD, many individuals who would benefit from PR still have limited or no access.[33,22,18] The uptake of PR is highly variable between

and within countries due to unequal availability and accessibility; insufficient planning, support, and communication to overcome barriers (see IPCRG desktop helper); use of models that are costly; and lack of integration of learned skills into daily life after the programme.[23,30,34-37] The proven health and cost benefits of PR have not been translated by payers into health service planning to address the emergent epidemic of noncommunicable disease.[18] Frequently, they fail to mandate the service.

It is our opinion that there is lack of investment in non-pharmacological treat-ment and research. Potentially, lessons can be learned from the success of other rehabilitation and supported self-management programmes.

What specifically can you do to improve access?

Ensuring that PR is accessible to all who would benefit from it is a major step towards improving the quality of life for patients with diagnosed chronic lung conditions like COPD, bronchiectasis or idiopathic pulmonary fibrosis (IPF).

Accessibility of a programme is achieved by systematically addressing the organisational barriers that prevent appropriate staffing, referrals, or attendance (due to lack of personal or public transport).

Affordability depends on the right programme length and intensity, efficient use of skills, and use of available primary care and community resources.

Acceptability will depend on social and cultural norms, and will benefit from actively engaging participants and their carers in the design of services. We propose adopting the Very Brief Advice model: **Ask, Advise and Act**; to help referrers learn to refer successfully. See the IPCRG Desktop Helper for more guidance and ways to overcome the fear many chronically breathless people have of an exercise-based intervention.

Sustainability will depend on providing PR "graduates" access to future programmes and activities to maintain the benefits achieved. These need to be accessible, affordable, and acceptable, and have an impact on physical and psychological wellbeing. Workforce training needs to be evidence-based, particularly as the evidence of how best to deliver the programmes is generated[7] and locally contextualised.[27]

We propose a **statement of intent** that clearly shows the benefits to patients, society and to government:

We demand that pulmonary rehabilitation is made available to our communities. It is a relatively low cost, highly effective, and acceptable intervention that helps significant numbers of people who are isolated and limited by their chronic breathlessness self-manage their condition, maintain their independence, and stay well, so they are less likely to require expensive unplanned healthcare interventions like admission to hospital. We call for research funding to evaluate how to tailor community-based programmes to local need, financial resources, and supply of healthcare workers; and standardised protocols to enable comparison between programmes.

See the Pulmonary Rehabilitation Desktop Helper and online resources for a practical guide to setting up simple services, and for clinician guidance and video consultation examples on how to explain and refer successfully. www.ipcrg.org/PR All resources are open access and free to use and translate under Creative Commons licences.

Conclusion

PR is healthcare based on practical, scientifically sound, and socially acceptable methods and technology that can be universally accessible to individuals in urban as well as rural and remote settings.

Pulmonary rehabilitation should be accessible to all. It is an effective non-pharmacological approach that can make a real difference to people's lives and reduce the burden on our hospitals and healthcare systems. With creativity and commitment, we can reduce the impact of breathlessness and chronic cardio-respiratory problems on disability, isolation and premature mortality. We can support families and communities by helping people who are chronically breathless remain productive members of society.

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