# LET'S TALK ABOUT PULMONARY REHABILITATION (PR)

## A step-by-step guide to introduce patients to PR

## Background

Lung Health @home is part of NHS @home - a range of initiatives that transform health and care services by adopting personalised care approaches to improve people's quality of life, and support people to keep well, recover and manage their health and well-being at home.

The aim of the project is to support more people to manage their lung condition at home and increase access to pulmonary rehabilitation (PR) for people with moderate to severe breathlessness. This will be achieved by:

1. Improving access to pulmonary rehabilitation (PR) through case finding and prioritisation and by improving and personalising the pathway.
2. Increasing access and participation in supported self-management, education, exercise, and other activity.

Despite a considerable body of robust evidence that supports the effectiveness of PR (McCarthy et al., 2015, Puhan et al., 2016), there is significant variation in referral rates across England (Singh et al., 2020). A rapid review of the literature found that there are several factors that facilitate or impede patient engagement in PR (Blank et al., 2022) from the patient, staff, and organisational perspective. These barriers include:

- The ability of staff to effectively communicate and engage patients in discussions about PR.
- Staff lacking knowledge of PR, the eligibility criteria and referral process.
- Staff and patients lacking understanding about the benefits of PR and exercise.
- Lack of access to robust patient information about PR.

## Purpose of this guide

Many healthcare professionals (HCPs) believe the most likely source of referral to PR is at a patient's annual review. However, there are other situations where primary care staff may be able to support patients to make a shared decision and initiate a referral. HCPs do not need to be an expert in respiratory care or PR to incorporate these shared decision-making conversations into routine consultations and these conversations do not need to take a long time.

Research shows that Very Brief Advice (VBA) can play an important role in how conversations are structured and has been shown to be a very effective approach in other areas of health care (Weight Management, PHE; Papadakis & McEwen, 2021).

We know if conversations about PR go well and patients view them positively, patients are more likely to want to be referred, attend and then complete the PR programme. The aim of this guide is therefore to:

- Increase healthcare professional's knowledge and confidence in PR.
- Increase healthcare professionals' skills in having a brief shared decision-making (SDM) conversation about PR.
- Direct healthcare professionals to suitable patient resources about PR.

## How was this guidance developed?

This guide was developed as part of the Lung Health @home project. Led by experienced clinicians in respiratory care, those with expertise in behaviour change and shared decision-making, and patients with a lived experience.

The content and format have been informed by the barriers and enablers to engaging in PR identified a rapid review of the literature (Blank et al., 2022), evidence-based approaches to behaviour change, including VBA and guidance on shared decision making (NICE, 2021).

# Preparing to have a conversation about PR.

Many healthcare professionals in primary care feel they are insufficiently trained in who to refer to PR (Early et al., 2020) so to help here is a reminder.

Table 1. PR referral criteria (Bolton et al, 2013)

| Inclusion criteria | Exclusion criteria |
|---|---|
| • Patients with a confirmed diagnosis of COPD, asthma, idiopathic pulmonary fibrosis (IPF), interstitial lung disease (ILD) or bronchiectasis<br>• Patients with an MRC score of 3 or more<br>• Functionally limited by breathlessness<br>• Patients who have either recently had an exacerbation of COPD requiring a hospital admission or whose functional baseline has significantly altered and is not following the expected recovery path. | • Unstable cardiovascular disease e.g., unstable angina or arrhythmias<br>• Recent myocardial infarction (MI)<br>• Abdominal aortic aneurysm (AAA; size dependent) |

As well as the national requirements, it is important that you become familiar with your local PR service so that you can have an informed conversation about PR with your patient. This is especially important given that not every person with breathlessness will have access to the same PR service. You will therefore need to know the following:

- Is there any variation in your local referral criteria?
- Where is the service located?
    - Is it accessed in primary care or your acute respiratory department?
    - Is it delivered in a health care setting or in the community?
- What does the service consist of and who delivers it?
- What time/day does it run? How could the patient get there?
- Are there digital or hybrid programs that can be accessed from home?
- What is the waiting time for assessment and attendance at PR?
    - Nationally the average waiting time to attend PR is 84 days (NACCAP, 2019)
- How do you refer people?

This is not information that will be the same across all services and could change overtime, so it is important to keep your knowledge up to date. You should also familiarize yourself with the infographic that supports this document, it is an easy-to-follow step-by-step conversation guide that outlines four steps to having a positive and supportive conversation with your patients.

## 1. Ask

The first step in the conversation is to understand the functional and psychosocial impact your patient experiences because of their breathlessness and the areas of their life that matter to them. Understanding this will enable you to personalise the conversation and identify how important it is to relieve the symptoms they are experiencing.

To do this the patient will need to understand what you mean by breathlessness. Sometimes breathlessness is long term and people experience it most days. This long-term breathlessness is known as chronic breathlessness. It develops gradually and lasts for weeks, months or years. Sometimes people also cough, bring up phlegm or feel wheezy. Patients might also get out of breath suddenly and unexpectedly; this is called acute breathlessness.

There are several phases' you could use to initiate this conversation, examples are:

**"How is your breathing affecting your everyday life?"**

**"What aspects of your COPD would you like to focus on?"**

**"What does your breathing stop you from doing?"**

**"What goal do you have in regard to your breathing?"**

**"In what ways are you restricted in your everyday life because of your breathing?"**

When having this discussion communicate to your patient in a way they can understand, use clear language, avoid jargon, and explain technical terms. Patients might use other terms such as shortness of breath or wheeziness, so adapt your language accordingly.

Responses could include playing with my grandchildren, walking upstairs, or dressing without being out of breath, walking to the shops, speaking in full sentences, or feeling less anxious.

Ensure your questions are open ended, show empathy and acknowledge their values and preferences. At the end summarise their health problem, to show that you have listened.

## 2. Introduce

Many patients may be unaware that they can and should participate in decisions about their care and treatment. This is your chance to let them know a choice exists and invite them to participate in the process. It is important that you ask their permission to tell them more about PR. A phrase you could use is:

**"We have a programme that could help you. Would it be ok if I told you more about it and I can support you to decide whether you would like to attend?"**

## 3. Shared decision

This is where you support your patient to make an informed, shared decision about referral to PR. It is important, if the patient chooses, that they involve family members,

friends, carers, advocates, or other people in the decision-making process.

This is when you assess what your patient already knows about PR and present what PR is, along with the pros and cons. A conversation starter could be:

**"What have you heard about pulmonary rehabilitation?"**

This will enable you to learn more about their values and preferences and address any misconceptions or barriers that they may have. Based on what we know from research (Blank et al., 2022) your patient may believe:

- Exercise isn't safe for them.
- They don't have the energy to go to PR.
- They are a smoker, so is there any point?
- They can't get there (e.g., travel or caring commitments).
- They don't have the right clothes (e.g., gym wear and trainers).

Table 2 provides you with a summary of the pros and cons of PR, which may help you to support your patients in deciding. It is important to tailor the *'What does PR involve?'* section to what is delivered in your local area. It is also important to communicate that there is the option to do nothing and not be referred to PR. This means their care will continue as usual.

Help your patient move to a decision by guiding them through the information in Table 2 and asking if they have any additional questions or would like more information to help them decide. They may want and need more time.

## 4. Action

If the patient is open to a referral this is the time to follow your local processes and explain to the patient what the next steps are. If your patient wants more time to think about the decision, to involve others or find out more schedule a follow-up conversation.

Ensure you make note of the conversation and the outcome in their notes, so that the conversation can be followed up by other colleagues at their next consultation. Either by checking in on their attendance or repeating this step-by-step guide. This also ensures your colleagues are aware of the conversation.

Provide them with paper copies or links to Asthma + Lung UK information about PR and other relevant educational materials. A comprehensive list of evidence-based resources for patients with respiratory condition and a guide on how to use the list can be found on the Lung Health @home website.

Table 2. Pros and cons of PR

| What does it involve? | PR involves attending a venue with a group of between 8 and 24 people, all of whom have a condition affecting their breathing. The venues are normally either at your local hospital, community hall, leisure centre or health centre. The group is supervised by a trained team of healthcare professionals who are experienced with working with people with chronic breathing conditions and are skilled at delivering PR. The programme runs for at least 6 weeks and |
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<tr><td></td><td>includes a 2-hour session twice a week. The programme consists of the following elements:<br>• an initial assessment about your breathing and how it affects your life.<br>• An initial physical assessment and walk tests to determine suitability and personal needs.<br>• Supervised physical exercise, which is individually graded to your specific ability.<br>• information and education about your condition and how to manage your breathing.<br>• an individualized plan for ongoing exercise after the programme finishes.<br><br>To get the most benefit from PR you need commit to attending all the sessions. Many PR programmes have a register and if you are unable to attend on 2 or more occasions you may be asked to restart the programme later.</td></tr>
<tr><td>Advantages</td><td>If you attend PR, you will:<br>• learn how to better control your breathlessness.<br>• meet other people with breathing conditions experiencing the same problems as you.<br>• gain information, advice, and support about living with a lung condition.<br>• Be able to talk to others about how it feels to live with a lung condition.<br>• Gain confidence from exercising with supervision from a therapist.<br>• Have a correct level of exercise 'prescribed' accurately by your therapist always ensuring your safety.<br><br>If you attend PR, the research suggests you:<br>• Are less likely to be admitted to hospital with a breathing condition and likely to have a shorter stay if you are.<br>• Will feel less tired and breathless.<br>• Will feel less anxious and depressed.<br>• Will feel a sense of control over your condition.<br>• Will experience fewer and less severe breathing symptoms.<br>• Will be able to do more activities that would normally affect your breathing or that you wouldn't normally be able to because of your breathing.<br>• Will improve your heart and lung health.<br>• Will be able to walk further.</td></tr>
<tr><td>Disadvantages</td><td>• You will have to travel to a venue for the initial assessment and the programme.<br>• The sessions will be held on a set time and day.<br>• You will need to also exercise at home in between supervised sessions.<br>• The programme needs you to commit at least 2 hrs twice a week, for at least 6 weeks.<br>• There is an extremely small chance that you could experience an injury whilst exercising.<br>• The exercise is hard work and will make you moderately breathless.</td></tr>
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## Other resources

If you are interested in learning more and developing your skills in shared decision making, behaviour change or personalised care we recommended you review the training opportunities identified by the Lung Health @home team. These can be found on the Lung Health @home website.

## References


- Adult weight management: short conversations with patients. Public Health England. Adult weight management: short conversations with patients - GOV.UK (www.gov.uk). Last updated March 2021.
- Bolton, C.E., Bevan-Smith, E.F., Blakey, J.D., Crowe, P., Elkin, S.L., Garrod, R., Greening, N.J., Heslop, K., Hull, J.H., Man, W.D-C., Morgan, M.D., Proud, D., Michael Roberts, C., Sewell, L., Singh, S,J., Walker, P.P. & Walmsley, S. (2013). *Thorax*, 68 (Suppl. 2), i1-i30.
- Blank, L., Cantrell, A., Sworn, K. & Booth, A. (2022). *Factors which facilitate or impede patient engagement with pulmonary and cardiac rehabilitation: a rapid evaluation mapping review. Southampton: NIHR Health and Social Care Delivery Research Topic Report*. DOI: https://doi.org/10.3310/hsdr-tr-135449.
- Early, F., Wilson, P.M., Deaton, C., Wellwood, I., Haque, H.W., Fox, S.E., Yousaf, A., Meysner, O.D., Ward, J.R., Singh, S.J.., & Fuld, J.P. (2020). Pulmonary rehabilitation referral and uptake from primary care for people living with COPD: a mixed-methods study. *ERJ Open Research*, 6(1).
- McCarthy, B., Casey, D., Devane, D., Murphy, K., Murphy, E., & Lacasse, Y. (2015). Pulmonary rehabilitation for chronic obstructive pulmonary disease. *The Cochrane database of systematic reviews*, (2), CD003793. https://doi.org/10.1002/14651858.CD003793.pub3
- National Institute for Clinical Excellence. (2021). *Shared decision making NG197*. https://www.nice.org.uk/guidance/ng197/resources/shared-decision-making-pdf-66142087186885
- Papadakis, S. & McEwen, A. (2021). *Very brief advice on smoking PLUS (VBA+)*. National Centre for Smoking Cessation and Training (NCSCT), Dorset, UK. September, 2021. https://www.ncsct.co.uk/publication_VBA+.php
- Puhan, M. A., Gimeno-Santos, E., Cates, C. J., & Troosters, T. (2016). Pulmonary rehabilitation following exacerbations of chronic obstructive pulmonary disease. *The Cochrane database of systematic reviews*, *12*(12), CD005305. https://doi.org/10.1002/14651858.CD005305.pub4
- Singh S, Latchem S, Andrews R, Garnavos N, Long N, Stone P, Adamson A, Quint J, Roberts CM. *National Asthma and Chronic Obstructive Pulmonary Disease Audit Programme (NACAP). Pulmonary rehabilitation audit report 2019. Combined clinical and organisational audit of pulmonary rehabilitation services in England, Scotland and Wales*. London: RCP, 2020.