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# Triangulated perspectives on outcomes of pulmonary rehabilitation in patients with COPD: a qualitative study to inform a core outcome set

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## Abstract

**Introduction:** Pulmonary rehabilitation implies a comprehensive assessment. Although several outcomes are commonly measured, those are selected mainly by health professionals and researchers, with the voice of patients and informal caregivers being minimally captured. Qualitative studies are fundamental to enhance our knowledge on perspectives of different stakeholders involved in pulmonary rehabilitation.

**Objective:** This study aimed to explore the views of different stakeholders on outcomes of pulmonary rehabilitation, contributing to one of the stages of a core outcome set for pulmonary rehabilitation in patients with chronic obstructive pulmonary disease (COPD).

**Methods:** Semi-structured interviews were conducted with 12 patients with COPD, 11 informal carers and 10 health professionals. Data were analysed with content analysis, followed by thematic analysis to gain deeper understanding of the different perspectives.

**Results:** A total of 44 outcomes were identified, being the most reported ‘improving functional performance’ (67%) and ‘reducing and taking control over dyspnoea’ (64%). Five relevant themes across stakeholders were generated: having a healthy mind in a healthy body; I can’t do it; feeling fulfilled; knowing more, doing better and avoiding doctors and expenses. Although perspectives were mostly consensual, some outcomes were only valued by health professionals (e.g. pulmonary function) or by patients and informal carers (e.g. quality of sleep).

**Conclusion:** Views of the different stakeholders on outcomes of pulmonary rehabilitation were similar although, some specificities existed. Comprehensive assessments are needed to reflect what is valued by the different stakeholders in pulmonary rehabilitation. This study contributed to a future core outcome set in this field.

## Keywords

Outcomes research, COPD, pulmonary rehabilitation, core outcome set

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## Introduction

Pulmonary rehabilitation is established as a fundamental intervention for the management of stable chronic obstructive pulmonary disease (COPD).<sup>1</sup> Although it is highly effective and more cost-effective than any pharmacological treatment, there are still patients that do not respond to this intervention.<sup>2</sup>

Moreover, this response is highly dependent on the outcomes and outcome measures selected by health professionals.<sup>3</sup> Thus, the choice of outcomes should be pondered, and elicit perspectives of the different key stakeholders.

The lack of homogeneity in outcomes and outcome measures used in pulmonary rehabilitation can hamper the conduction of meta-analysis and an accurate interpretation of the outcomes, which may mislead guidance to treatment.<sup>4,5</sup>

In order to overcome these barriers, the development of a core outcome set, defined as a minimum set of outcomes that should be consistently measured and reported,<sup>6</sup> in patients with COPD has been advocated.<sup>7-9</sup> A core outcome set has the potential to generate consistency among trials and lessen the risk of outcome reporting bias, by including outcomes relevant to different stakeholders.<sup>10</sup>

Although some studies have separately explored the views of patients and health professionals on specific aspects of pulmonary rehabilitation,<sup>11,12</sup> the outcomes of pulmonary rehabilitation valued by these two stakeholders have not been explored. Furthermore, the inclusion of informal carers' perspectives is scarce, and yet fundamental, as they have an important role on optimizing patients' outcomes.<sup>13</sup>

Thus, this study aimed to explore the perspectives of patients, informal carers and health professionals, on outcomes of pulmonary rehabilitation. This will inform a future core outcome set for pulmonary rehabilitation in patients with stable COPD.

## Methods

This study informs the development of a core outcome set for pulmonary rehabilitation in people with COPD that was registered in the Core Outcome

Measures in Effectiveness Trials initiative (<http://www.comet-initiative.org/studies/details/1151>). It was approved by the Ethics Committee of the Research Unit of Health Sciences at the School of Nursing in Coimbra (UICISA), Portugal (P466-10/2017).

All participants gave informed consent to take part in the study.

Patients and informal carers were recruited from 12-week pulmonary rehabilitation programmes. Health professionals were recruited from the Lab 3R – respiratory research and rehabilitation laboratory's network. Pulmonary rehabilitation programmes comprised exercise twice a week and education and psychosocial support once every two weeks. The pulmonary rehabilitation programmes are described elsewhere.<sup>14</sup>

Patients were included if diagnosed with COPD, of any age or gender, that initiated a pulmonary rehabilitation programme in a stable phase (i.e. no acute exacerbations in the last month)<sup>15</sup> and completed at least one programme. Informal carers were unpaid, significant people, named by patients ( $\geq 18$  years old), who supported them in their daily living activities, healthcare or offered emotional support.<sup>16</sup> Patients and informal carers were excluded if they had signs of depression or cognitive impairment (incoherent speech, lack of recent memories or abnormal behaviour).<sup>17</sup>

Health professionals were included if they had been involved in the design, support or implementation of at least one pulmonary rehabilitation programme including patients with COPD.

The sample size was determined by data saturation. Saturation was defined as the point when interviews did not generate relevant, additional outcomes.<sup>18</sup> A maximum variation strategy was used to guide the recruitment, using the following criteria:

- Patients: stage of the disease (GOLD I–IV and A–D), determined by spirometry,<sup>19</sup> the COPD Assessment test (CAT) and number of exacerbations;<sup>20</sup>
- Informal carers: years of caring;
- Health professionals: type of involvement in pulmonary rehabilitation programmes (design,

implementation, support), duration of their experience (quantified in years) and professional background (medical doctors, physiotherapists, nurses, psychologists, nutritionists were invited).

Sociodemographic data were collected from all participants.

Interviews were conducted in a semi-structured format, following a topic guide with open-ended questions and recorded with an audio recorder. This method has been described as a powerful approach to guide interviews, allowing participants to follow a line of reasoning, although maintaining the ability to express their feelings, which would not be possible using a rigid format.<sup>21</sup> The guide followed the theoretical framework of phenomenology and was informed by reading different systematic reviews of pulmonary rehabilitation in COPD and consulting an expert on qualitative interviews.<sup>22–24</sup>

Descriptive statistics were applied to characterize participants using SPSS statistics software version 23 (IBM, SPSS Inc, Chicago, Illinois). NVivo software was used to aid qualitative data organization and visualization (version 11, QSR International Pty Ltd, 2017, Victoria, Australia).<sup>25</sup>

The interview analysis was divided in two stages: the first to define a list of outcomes, using content analysis<sup>26</sup> and the second to gain in-depth knowledge of the views of different stakeholders on pulmonary rehabilitation, in which thematic analysis was used.<sup>27</sup>

The first stage was the transcription of interviews, which were checked for accuracy by two researchers and then coded by one of the researchers using inductive latent content analysis, where outcomes from participants' own words were gathered by content and (e.g. '... I can shower by myself, and I can also put my shoes on' '... I do not have to enter the shower to help him'. – improving functional performance). Outcomes were defined after transcription. An outcome was defined as a perceived consequence or impact, positive or negative, for people with COPD, their informal carers or health professionals, whether intended or incidental, arising from undertaking pulmonary rehabilitation. The percentage of participants of each

stakeholder group who mentioned each outcome was recorded. Views of all stakeholders were combined in a single list to inform in a simplistic, but simultaneously meaningful manner, the development of the core outcome set at this initial stage. This list will then be compared with outcomes prevalent from systematic literature reviews, forming a more comprehensive final list of outcomes. This final list will aid the consensus stage of the core outcome set development, where individual views of each stakeholder will be revisited.

Stage II identified outcomes with similar semantic meanings that followed the same patterns and were then collapsed and interpreted as themes to gain deeper understanding of the perspectives of the different stakeholders on pulmonary rehabilitation.<sup>27,28</sup>

To ensure the credibility of interpretation, memos and decisions were recorded throughout the analytical process. The outcomes collapsed into each of the themes were defined by reaching consensus between two independent researchers. Cohen's kappa was computed for the agreement between researchers.<sup>29</sup>

## Results

A total of 33 participants were interviewed (12 patients, 11 informal carers and 10 health professionals). Interviews lasted on average 45 minutes. Patients were mostly males, GOLD II according to airflow limitation severity ( $FEV_{1pp}$   $50.7 \pm 17.5$ , mean  $\pm$  standard deviation), and all groups (A, B, C, D) were represented. Informal carers were mostly females and were caring for  $5.3 \pm 7$  (mean  $\pm$  standard deviation) years. Health professionals and researchers were mostly females, who had been designing and implementing the pulmonary rehabilitation programmes ( $n=5$ , 50%) and had an average experience of seven years (minimum of one year and maximum 16 years). Table 1 describes the sample characteristics per stakeholder group.

Stage I resulted in a list of outcomes. A total of 44 outcomes were identified from the interviews. Data saturation was reached, with no new outcome being generated in the last two interviews of all stakeholders' groups.

**Table 1.** Characteristics of participants ( $n=33$ ).

	Patients ( $n=12$ )	Informal carers ( $n=11$ )	Health professionals ( $n=10$ )
Age, years	70.8 $\pm$ 5.2	68.4 $\pm$ 7.9	40.7 $\pm$ 14.3
Gender, $n$ (%)			
Male	10 (83.3)	2 (18.2)	2 (20)
Female	2 (16.7)	9 (81.8)	8 (80)
Occupation, $n$ (%)			
Restaurant owner	1 (8.3)	0 (0)	0 (0)
Retired	11 (91.7)	7 (63.6)	0 (0)
Housekeeper	0 (0)	4 (36.4)	0 (0)
Physiotherapist	0 (0)	0 (0)	2 (20)
Medical doctors	0 (0)	0 (0)	2 (20)
Nurses	0 (0)	0 (0)	2 (20)
Researchers	0 (0)	0 (0)	4 (40)
Total CAT, total score	13.8 $\pm$ 6.1	–	–
GOLD (I–IV), $n$ (%)	6 (50) II 4 (33.3) III 1 (8.3) IV	–	–
GOLD (A–D), $n$ (%)	5 (41.7) A 3 (25) B 1 (8.3) C 2 (16.7) D	–	–
Number of AECOPD on previous year	1 $\pm$ 1.0	–	–

GOLD: global initiative for chronic obstructive lung disease; I–IV airflow limitation increased with ascending order; A–D (ABCD) assessment tool: assessment of symptoms and exacerbation risk; CAT: COPD assessment test; AECOPD: Acute exacerbation of COPD.

Results are expressed in mean  $\pm$  standard deviation unless otherwise stated.

Most reported outcomes across all stakeholders were ‘improving functional performance’ (67%) and ‘reducing and taking control over dyspnoea’ (64%).

Of the 44 outcomes, 38 were perceived as positive outcomes and 6 as negative outcomes of pulmonary rehabilitation in five different themes (described in detail below in stage II). A more detailed description can be found in Supplemental material Table 1. Stage II resulted in five themes that explained the generated outcomes. Strong agreement between the two reviewers was found ( $\kappa=0.81$ ; Figure 1). Themes comprised several life dimensions with triangulated perspectives of the stakeholders.

The first theme ‘Being healthy’ refers to a regained sense of healthiness that patients felt, by restoring part of their physical capacity, which

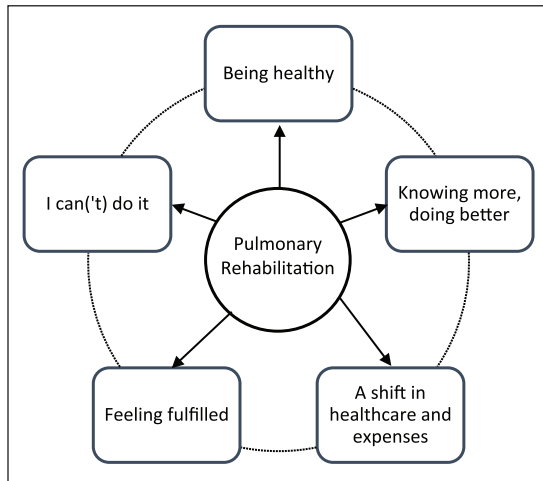
allowed them to engage in activities with their loved ones with less effort.

Patients felt proud of their new skills to face day-to-day challenges and of being more fit to perform functional tasks without the help of a third-party. Overall, they had a generalized feeling of well-being, of whole body equilibrium, no longer feeling trapped in a sick body.

These improvements had a positive impact on informal carers, as they showed contentment by seeing patients’ improvements in general health and how they became stronger.

Health professionals felt gratified as pulmonary rehabilitation gave back patients’ functionality to perform daily living activities, becoming part of the society again and regaining a role in their families.

Through improvements in respiratory symptoms and restless nights, patients and informal



**Figure 1.** Thematic map.

carers felt that there was a boost in stamina to do more tasks on a day-to-day basis.

Although most of the outcomes were seen as positive, patients and informal carers felt pulmonary rehabilitation also caused pain and fatigue on the day after the physical exercise sessions, limiting their ability to help on domestic tasks and participate on family or group activities.

As pulmonary rehabilitation gave patients tools not only to control symptoms but also to become less afraid of the course of the disease, there was a symbiotic relationship between a healthier mind and a healthier body:

Now I can take a shower by myself, and I can also put my shoes on. – JC (patient)

Before, when we went walking together he had to stop and do something. Now he comes with me and walks without stopping. I think that now I get tired faster than him. – IA (informal carer)

What I value most in pulmonary rehabilitation is the quality of life it gives to patients. They become more integrated in their families and in the society. – AC (health professional)

The theme ‘I can(’t) do it’ shows that pulmonary rehabilitation resulted in a modulation in patients’

perception of their capacity to achieve goals, as they became more confident of their own abilities. Indeed, by acknowledging their potential, patients freed themselves from self-established limitations and became more lively and hopeful of their future.

Similarly, health professionals felt patients they coped better with the disease and its consequences regaining hope about their health status and longevity.

Patients improved their mood and motivation, enjoyed the sessions and established connections with each other and staff personnel. Informal carers felt patients became happier about their lives, more talkative with other people and laughed more often. Participants felt pulmonary rehabilitation brought them motivation to face life challenges, and to be more proactive within the community:

I started to realise that I could do things, some limitations were in my head. – JC (patient)

... she started to feel more motivated, more opened, more available to face the challenges of her own life. – AB (informal carer)

I think that they cope better because they see that they are not the only ones with the problem, and when they see a patient with oxygen and realise that that person travels, goes on a plane and does everything they like to do, the situation becomes less of a monster. – TP (health professional)

The theme ‘Feeling fulfilled’ was connected with the previous theme as the modulation in self-perception of achievements had a relevant impact on patients’ fulfilment.

By improving self-confidence, patients found encouragement to seek a new purpose and meaning in life.

Pulmonary rehabilitation brought patients a sense of fulfilment, as they recovered freedom from their carers and were proud to return to their roles within the family.

Patients stopped seeing themselves as ‘the patient’ and more like the husband and the father of someone, recalling the person they used to be before the disease.

The strong family support system and pulmonary rehabilitation staff provided the opportunity



for patients to find a new sense of self and belonging, developing new friendships and hobbies, such as volunteering.

Patients felt their embarrassment in social occasions decreased, since they realized they were not the only ones with the disease. Identically, health professionals felt patients' frustration decreased with their fulfilment with life and their ability to accomplish tasks again, leading to a sense of self-efficacy.

Furthermore, health professionals' views were that patients' sexual life improved, as they learned how to control dyspnoea and fear of adverse events, which contributed to their fulfilment with life:

I used to be ashamed, because I wasn't able to do things like the others, because I was different. When I started having these breathing problems it all emerged, and then it went away with the pulmonary rehabilitation programme. – AB (patient)

While some people languish due to the disease, here it was not the case. Since she went to the pulmonary rehabilitation programme – she came out of her shell, she started volunteering and wanting to do new things. – AB (informal carer)

People that are very isolated come to the pulmonary rehabilitation programme and start sharing rides ... later on, they come to our parties (e.g., Christmas, Worldwide days), see friends they made when they were in the programme and make plans to meet outside the programme. Some things they don't tell us but we see. – AO (health professional)

The theme 'Knowing more, doing better' showed that learning about the disease, management strategies and support network allowed patients to handle better their acute exacerbations and mental health issues.

This theme was related with the theme 'Feeling fulfilled', as patients felt pulmonary rehabilitation gave them new insights and a will to engage in support groups by feeling free from preconceived ideas.

Health professionals felt pulmonary rehabilitation gave patients tools for an effective self-management and that demystifying negative beliefs, such as not leaving home to avoid sickness, helped patients in an 'enormous way'.

Moreover, informal carers shared that they became calmer, more relaxed, by knowing how to help patients in difficult situations and that nothing bad was going to happen:

A lot of people still lack health education and here we learn a few things that make us want to know more and search. – AB (patient)

When I go swimming, I am more relaxed now. Before, I used to take my mobile phone with me to the swimming pool and ask the teacher to call me if my phone rang. I used to go shopping in a rush, and now I feel that he's doing better and I am calmer. – MC (informal carer)

Some beliefs are prejudicial to patients and impair the results of the intervention. Sometimes, demystifying a belief is helping the patient in a great way. And sometimes, people surrounding the patient have maladjusted beliefs that limit them. Involving the family is very important. – PA (health professional)

The theme 'A shift in health care and expenses' refers to the gains patients had in learning how to better self-manage themselves and how to deal with their symptoms, which resulted in less emergency visits and medication-related costs.

Patients and informal carers recognized general health improvements, with a decrease in the use of short-acting inhalers and oxygen debit, relating it to a better health prospect. The acknowledgement by health professionals of the decrease in health-care utilization was seen as a good indicator of maintaining their health-related physical fitness and quality of life.

Although health professionals felt the expenses with pulmonary rehabilitation were balanced by the decrease in healthcare utilization, patients and informal carers thought the expenses with fees and transports were not bearable for everyone, which frequently led to dropping out or not even adhering to the pulmonary rehabilitation programmes.

Thus, participants felt that having the pulmonary rehabilitation programme close to their homes, in the community, was both more convenient and less scary than in hospitals:

Now I use the inhaler less frequently. I used to take that medication several times a day and now I rarely use it. – JV (patient)

One year ago, by this time of the year, she spent the winter sick and we couldn't do anything. This year I ask her to go out with me because I see that she is doing well. – AM (informal carer)

It ends up being a positive effect because they spend money on the program but save it on several other things such as medication and hospitalisations. – FM (health professional)

Figure 1 provides a thematic map with the connections between these different themes after undertaking pulmonary rehabilitation.

## Discussion

This qualitative study resulted in a list of outcomes of what should be measured in pulmonary rehabilitation, from the perspectives of different key stakeholders (patients, informal carers and health professionals), thus contributing for a future core outcome set for pulmonary rehabilitation in patients with COPD. This study also informed the methodology to develop core outcome sets, as there are seldom qualitative studies within core outcome sets, exploring the perspectives of the different key stakeholders.

A list of 44 (38 positive and 6 negative) outcomes, was developed and conceptualized under five themes, that is, Being healthy; I can('t) do it; Feeling fulfilled; Knowing more, doing better and A shift in healthcare and expenses. These results can now be compared with outcomes described in systematic literature reviews of pulmonary rehabilitation in COPD, to identify outcomes that are relevant to (1) all stakeholders and commonly measured, (2) all stakeholders and rarely measured, (3) some stakeholders and commonly measured and (4) some stakeholders and rarely measured.

Positive outcomes valued by all stakeholders, such as 'improving exercise tolerance' and 'reducing and taking control over dyspnoea' are well-recognized benefits of pulmonary rehabilitation, and studies usually use the same outcome

measures.<sup>30–32</sup> Therefore, these outcomes are likely to integrate a future core outcome set for pulmonary rehabilitation.

Although 'improving functional performance', 'managing fatigue, improving stamina and exercise recover', 'staying motivated and feeling confident', 'having meaningful support' and 'having a purpose, feeling of self-efficacy', were valued outcomes among all stakeholders, their assessment in pulmonary rehabilitation is not standardized and is rarely reported in the literature.<sup>30–32</sup> Functionality is fundamental, as it translates to patients' quotidian and influences informal carers' burden.<sup>33</sup> Fatigue is one of the major symptoms limiting patients; therefore, its common/routine assessment for adequate management is important.<sup>34</sup> Motivation is the drive for behaviour change and is influenced by many factors.<sup>35</sup> Despite being well described that patient's motivation towards exercise affects adherence to pulmonary rehabilitation,<sup>36</sup> little is known about the role of pulmonary rehabilitation on patient's motivation. Since pulmonary rehabilitation might be a vector in changing behaviours and adapting to a healthier lifestyle, motivation seems an important outcome to be assessed. 'Having meaningful support' was also a valued outcome by all stakeholders. The inclusion of family in pulmonary rehabilitation has shown positive effects on family coping<sup>33,37</sup> and informal carers are the main source of support for patients with COPD;<sup>38</sup> therefore, pulmonary rehabilitation might be a possible response to build a meaningful support to those identified as in need. 'Having a purpose, feeling of self-efficacy', is also a crucial outcome to be measured in pulmonary rehabilitation, as it can play as a synergist or antagonist to other important clinical outcomes, such as attendance or exercise tolerance.<sup>39</sup> Thus, health professionals must be aware of patients' baseline self-efficacy perception in order to guide pulmonary rehabilitation into a successful pathway. This is a good example where the development of a core outcome set could be useful to ascertain response to pulmonary rehabilitation, since the perspectives of all stakeholders on these positive outcomes were consensual.

Conversely, some outcomes, both positive and negative, that is, 'reducing pulmonary function



decline', 'reducing depression' and 'reducing healthcare utilisation' were only valued by health professionals, but are commonly measured. Thus, the importance of these outcomes for the other stakeholders and their relevance to be included in a core outcome set for pulmonary rehabilitation needs to be further investigated.

Finally, some outcomes were only valued by either health professionals (e.g. 'improving body awareness', 'increasing the impact on comorbidities', 'keeping an active sexual life' and 'increasing social embarrassment and frustration') or patients and informal carers (e.g. 'improving well-being', 'improving the quality of sleep' and 'improving the predisposition to hobbies') but are rarely measured. Although these outcomes were valued by some stakeholders, their response to pulmonary rehabilitation and respective role to be included in a core outcome set needs further clarification.

Negative outcomes were also reported by all stakeholders. These outcomes need careful consideration, as they are rarely reported in the literature but may lead to poor adherence to the intervention.<sup>12,40,41</sup>

Finally, concerns such as financial and geographical constraints were clearly identified by all stakeholders. These outcomes are recognized barriers for the implementation of pulmonary rehabilitation.<sup>9</sup> It might be valuable to measure them routinely, as they can limit access to this essential and well-established intervention for patients and families.

Considering the complexity of this disease, assessments should follow the principal of comprehensiveness implied in the intervention and include multiple areas of life, in order to reveal the unique characteristics/needs of patients, which might help decision-making within the multidisciplinary team and personalize interventions to each patient.<sup>2</sup> Similar results have been found for acute respiratory failure, where multiple life dimensions were considered essential to be measured by key stakeholders.<sup>42</sup> Thus, this study adds value to a future core outcome set that has the potential to improve the quality of care to patients with COPD, by being meaningful and useful for research and clinical practice in pulmonary rehabilitation.

This study has some limitations that need to be acknowledged. Since the coding of outcomes from the interview transcripts was performed only by one researcher who was conducting this research, some bias might have occurred. However, having more than one researcher coding has been found to somewhat restrict the interpretation of data and impair the following stages of the analysis.<sup>43</sup> Another potential limitation of this study is the diversity of health professionals included. Since pulmonary rehabilitation includes a multidisciplinary team, it is possible that including other professionals would generate additional outcomes. However, we have included the most common health professionals involved in pulmonary rehabilitation around the world, and data saturation was reached in all stakeholders.

The results of this study revealed a need for bridging the gap between researchers, health professionals, patients and families involved in pulmonary rehabilitation as typically outcomes are commonly selected by health professionals and researchers, with the voice of patients and informal caregivers being minimally captured. In fact, although perspectives were mostly consensual among stakeholders, some outcomes were only valued by health professionals (e.g. pulmonary function), while others only by patients and informal carers (e.g. quality of sleep). This highlights the mismatch between the reported outcomes in the literature (mainly influenced by health professionals and researchers) and those reported by key stakeholders, which is of most concern as it impairs personalized pulmonary rehabilitation.<sup>44</sup> This issue has been shown in previous studies, where patients and family members valued different outcomes when compared to researchers.<sup>42</sup>

This study also gives new insights for future studies aiming to explore the differential response of patients with COPD to pulmonary rehabilitation. Although this qualitative study intended to inform the development of a core outcome set, future studies could focus on outcomes reported by these stakeholders that are seldom present in the literature, and yet highly meaningful not only to patients but also to their carers and health professionals. In addition, negative outcomes should be investigated

to ensure a better management within pulmonary rehabilitation, as they impact on patients' and carers lives.

### Clinical Messages

- Patients, informal carers and researchers valued outcomes of pulmonary rehabilitation related to being healthy; I can(t) do it; Feeling fulfilled; Knowing more doing better; and A shift in healthcare and expenses.
- Pulmonary rehabilitation assessments should integrate outcomes relevant to all key stakeholders including those rarely measured nowadays, such as functionality, fatigue, motivation, social support and self-efficacy.
- Negative outcomes should be considered when conducting a pulmonary rehabilitation programme, as they may play an important role on its success.

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### Supplemental material

Supplemental material for this article is available online.

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