



International perspectives on outcome measurement in pulmonary rehabilitation of COPD

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Abstract

Heterogeneity of outcomes and measures limits benchmarking pulmonary rehabilitation (PR) and effective evidence synthesis. A core outcome set (COS) can minimise this problem. However, it is unclear which outcomes are important for different stakeholders.

1-to-1 interviews were conducted with people with COPD, healthcare professionals (HCPs), researchers and policymakers. Content analysis was conducted for the frequency of outcomes viewed as crucial or not, and a thematic analysis to better understand stakeholders' views.

37 participants (17 people with COPD and 20 HCPs/researchers/policymakers) from 14 countries were included. Participants expressed that i) core outcomes need to be meaningful to people with COPD and show PR benefits; ii) there should be comprehensive and similar outcome measurement in all settings; iii) a balance between optimal and practical measures is needed; iv) a COS is needed to benchmark PR and advance knowledge; and v) reluctance to change of outcomes/measures used by HCPs and using the COS as a maximum set of outcomes might be the pitfalls. 28 outcomes were identified as crucial, and 12 as non-crucial. There were also differences in perspectives within and between stakeholder groups about 8 outcomes (**Table 1**).

This study provided important insights into outcome measurement in PR and a list of outcomes that will inform a future consensus study.

Table 1. Outcomes reported by the different stakeholders as crucial, non-crucial, and outcomes with discrepant views.

Crucial outcomes	Non-crucial outcomes	Outcomes with discrepant views
Exercise capacity	Lung function	Lung function
Dyspnoea	Handgrip strength	Muscle strength
Anxiety, distress, depression, general mood, and disease-specific fears	Physical activity	Physical activity
Muscle function and strength	Cognitive function	Self-efficacy
Functional status and ADL	Muscle strength	Anxiety and depression
Health-related quality of life	Anxiety and depression	Exercise capacity
Physical activity	Exercise capacity	Body mass index
Fatigue/Loss of energy	Respiratory muscle function	Balance
Lung function	Self-efficacy	
Social status	Body mass index	
Knowledge	Balance	
AECOPD	Swallowing function	
Sleep		
Coping strategies		
Healthcare utilisation		
Self-efficacy		
Pain		
Cough		
Motivation		
Frailty		
Oxygen saturation		
Care dependency		
Fat mass, fat free mass and phase angle alpha		
Balance/Agility		
BMI		
Energy expenditure		
Smoking cessation		
Biomarkers/blood analysis		

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