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Differences in content and organizational aspects of pulmonary rehabilitation programs

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TAKE HOME MESSAGE

Differences in aspects of pulmonary rehabilitation programs suggest caution in generalisation of research findings.

ABSTRACT

Objective: To study the overall content and organizational aspects of pulmonary rehabilitation programs from a global perspective to get an initial appraisal on the degree of heterogeneity worldwide.

Methods: A twelve-question survey on content and organizational aspects was completed by representatives of pulmonary rehabilitation programs that previously participated in the European Respiratory Society (ERS) COPD Audit. Moreover, all ERS members affiliated with the ERS Scientific Groups 01.02 (Rehabilitation and Chronic Care) and/or 09.02 (Physiotherapy), all members of the American Association of Cardiovascular and Pulmonary Rehabilitation (AACVPR), and all ATS Pulmonary Rehabilitation Assembly members were asked to complete the survey via multiple e-mailings.

Results: The survey has been completed by representatives of 430 centres from 40 countries. The findings demonstrate large differences among pulmonary rehabilitation programs across continents for all aspects that were surveyed, including the setting, the case-mix of individuals with a chronic respiratory disease, composition of the pulmonary rehabilitation team, completion rates, methods of referral, and types of reimbursement.

Conclusions: The current findings stress the importance of future development of process and performance metrics to monitor pulmonary rehabilitation programs, to be able to start international benchmarking, and to provide recommendations for international standards based on evidence and best practice.

(200 words)

KEYWORDS

Process metrics

Performance metrics

COPD

Pulmonary rehabilitation

INTRODUCTION

Pulmonary rehabilitation is defined as a comprehensive intervention based on a thorough patient assessment followed by patient-tailored therapies, which include, but are not limited to, exercise training, education and behaviour change, designed to improve the physical and psychological condition of people with chronic respiratory disease and to promote the long-term adherence of health-enhancing behaviours (1). Pulmonary rehabilitation has consistently shown that individuals with chronic respiratory disease experience a decrease in daily symptoms of dyspnea, fatigue, anxiety, and depression; improvements in exercise performance, self-efficacy, and health status; and a decrease in healthcare utilization (2-9). As pulmonary rehabilitation addresses the symptoms, activity limitations and reduced health related quality of life associated with chronic respiratory disease, it is now considered a fundamental component of the integrated disease management of individuals with chronic respiratory disease (10).

Although pulmonary rehabilitation should be made available to all individuals with chronic respiratory disease who still suffer from daily symptoms despite optimal medical therapy (1), there are still marked shortfalls in the provision of this intervention (11-15). Moreover, there is variability in content and organizational aspects among pulmonary rehabilitation programs at a national level (11, 14-17). This is most probably the result of local conditions, and not the reflections of an evidence based organizational model. Differences in content and organizational aspects may partially explain the differences in reported outcomes following pulmonary rehabilitation (18).

To date, neither the content nor the organizational aspects of pulmonary rehabilitation programs have been studied worldwide during the same period of time. As international differences may limit international benchmarking (19), the overall content and organizational aspects of

pulmonary rehabilitation programs from a global perspective were studied to get an initial appraisal on the degree of heterogeneity worldwide.

METHODS

Study design

An existing survey on pulmonary rehabilitation was made available for this project by Brooks et al. (11, 16). The survey was shortened to twelve questions. The response format was either a checkbox or free text option (see online-only supplement for details of survey). From September 2012 to February 2013, pulmonary rehabilitation programs that previously participated in the European Respiratory Society (ERS) COPD Audit, were asked to complete this survey (n=384). Moreover, all ERS members affiliated with the ERS Scientific Groups 01.02 (Rehabilitation and Chronic Care) and/or 09.02 (Physiotherapy) (n=983), all members of the American Association of Cardiovascular and Pulmonary Rehabilitation (AACVPR, n=1628), and all ATS Pulmonary Rehabilitation Assembly members (n=486) were asked to complete the survey via multiple e-mailings. There may have been overlap, as people can be affiliated to two or more of the abovementioned groups. Moreover, not all recipients of the e-mail are working in a pulmonary rehabilitation setting. Surveys were returned by e-mail or air mail. All data were inserted into an excel database. Respondents were contacted via e-mail if data were missing. Pulmonary rehabilitation program starting after 2011 were excluded. Only complete surveys were used for further analyses. Only one survey per pulmonary rehabilitation program was included in the analyses (i.e., only the first received completed survey per pulmonary rehabilitation program was used).

Statistical analyses

GraphPad Prism 5, Excel and SPSS were used for the statistical analyses. Median (interquartile range, IQR) and proportion were calculated, as appropriate. *A posteriori*, differences between Europe and North America were analysed using a Wilcoxon rank-sum test or Chi square as these were the two continents with the highest number of completed surveys. The findings of the remaining continents were not clustered as the number of surveys was rather limited. *A priori*, the level of significance was set at ≤0.05.

RESULTS

General characteristics

A total of 481 surveys were returned from 40 countries. After excluding all surveys with missing data or overlapping pulmonary rehabilitation programs, 430 surveys were available for the final analyses. Most surveys were affiliated with pulmonary rehabilitation programs from Europe (43.7%) or North America (43.5%). The remaining programs were from Oceania, Asia, South America, or Africa (online-only supplement Fig. E1).

Setting

Most commonly, centres offered structured outpatient pulmonary rehabilitation programs (262 centres, 60.9%), 41 centres (9.5%) offered inpatient programs, and 106 centres (24.7%) offered both. The remaining 21 pulmonary rehabilitation programs (4.9%) offered rehabilitation in the home setting (including tele-rehabilitation), or the primary care setting. Most of these programs (17 of 21) were offered in combination with an inpatient or outpatient hospital-based pulmonary

rehabilitation program. Most programs in both Europe and North America were outpatient programs (Table).

Table. European *versus* North American pulmonary rehabilitation programs

	Europe (n=188)	**North America (n=187)**	P-value
Setting (% PR programs)			
• Outpatient	48.9	71.7	<0.001
• Inpatient	16.0	3.7	
• Both	29.3	23.0	
• Other	5.8	1.6	
Types of reimbursement (% PR programs) *			
• Own insurance	38.3	92.5	<0.001
• Government	62.8	38.5	<0.001
• Own money	10.6	43.3	<0.001
• Work insurance	3.7	19.3	<0.001
• Not funded	2.7	0.5	0.22
• Other	-	0.5	0.50
PR team members (% PR programs) #			
• Chest physician	87.8	62.0	<0.001
• Physiotherapist	95.2	17.1	<0.001
• Occupational therapist	36.2	17.1	<0.001
• Social worker	42.6	24.1	<0.001
• Psychologist	53.7	8.6	<0.001
• Dietician	76.1	93.5	<0.001
• Exercise physiologist	25.5	62.6	<0.001
• Internist	11.7	8.0	0.30
• Cardiologist	43.0	20.0	<0.001
• General practitioner	18.1	13.4	0.26
• Pharmacist	22.9	18.2	0.31
• Nurse	68.1	64.2	0.45
• Respiratory therapist	1.6	59.9	<0.001
Median (IQR) number of team members	6 (4 to 8)	4 (3 to 6)	<0.001
Referral sites (% PR programs) *			

• Chest physicians	96.8	95.7	0.60
• General practitioners	55.9	92.5	<0.001
• Self-referral	21.3	33.7	0.008
• Specialist respiratory nurse	12.2	3.7	0.001
• Cardiologist	1.1	9.1	<0.001
Median number of individuals per PR program (n)	76 to 105	46 to 75	<0.001
Estimated total PR enrollments in 2011 (n)	19,515	11,475	<0.001
Median proportion of PR completers (%) ‡	76 to 90	61 to 75	<0.001
Casemix (% PR programs) *			
• 'Stable' COPD	95.7	98.9	0.11
• 'Unstable' COPD	74.5	75.9	0.81
• Restrictive lung disease †	66.5	82.4	0.001
• Asthma	63.3	82.9	<0.001
• Post-thoracic surgery	61.7	85.0	<0.001
Median (IQR) length PR program (weeks)	8 (5.6 to 12)	11 (8 to 12)	<0.001
Median (IQR) number of PR sessions per week	2.5 (2 to 4)	2.5 (2 to 3)	0.005
Median (IQR) duration of PR session (hours)	2 (1.3 to 2)	1.5 (1 to 1.5)	<0.001
Median (IQR) total PR hours (weeks x sessions x time per session)	39.3 (25.0 to 62.5)	36 (30 to 48)	0.33
Most important outcomes (% PR programs) *			
• Quality of life	81.4	83.4	0.68
• 6-min walk test	33.0	53.5	<0.001
• Dyspnea	48.4	35.8	0.016
• Depression	3.2	9.1	0.019
• Physical activity	33.5	21.9	0.02
• Self-management skills	33.5	30.5	0.58
• Smoking cessation	5.9	16.0	0.002
• Activities of daily living	28.7	36.4	0.12
Interventions (% PR programs) *			
• Outdoor walking	43.6	5.9	<0.001
• Treadmill walking	68.6	97.9	<0.001
• Stationary cycling	89.4	97.3	0.003
• Resistance training using training apparatus	62.8	67.9	0.33
• Resistance training using handheld weights	71.3	93.6	<0.001
• Education	89.9	98.9	<0.001

• ECT / ADL training	64.9	94.7	<0.001
• Self-management training	75.5	85.0	<0.001
• Nutritional support	76.1	93.6	<0.001
• Inspiratory muscle training	54.8	49.7	0.35
• Neuromuscular electrical stimulation	29.3	1.6	<0.001
• Breathing exercise including PLB	86.7	97.9	<0.001
• Smoking cessation	76.6	83.4	0.12
• Psychosocial support	64.9	81.8	<0.001
Median (IQR) number of types of interventions	10 (8 to 12)	11 (10 to 12)	0.0041

***** sum of proportions exceeds 100% as respondents were allowed or asked to choose more than one option

Pulmonary rehabilitation team members with a prevalence of 10% or more in one or both continents

‡ 50% of the programs enrolled 76 to 105 (Europe) or 46 to 75 patients (North America) or more in 2011

† always including interstitial lung disease, and seldom also thoracic wall diseases

Types of reimbursement

A small number (6, 1.4%) of programs did not receive any reimbursement for providing pulmonary rehabilitation. The remaining pulmonary rehabilitation programs were funded by one or more sources (range one to five): individuals' insurance (58.8%); government (54.8%); individuals' own money (25.6%); workplace insurance (10.2%); or others, including but not limited to departmental funding, research grants, external funding, personal efforts, and private donations. Programs were more likely to be reimbursed in Europe by the government, while North American programs by the patient's insurance or own money (Table).

Team members

Pulmonary rehabilitation teams consisted of a median of 5 (IQR: 4 to 7) healthcare professionals (Fig. 1A). Chest physicians (70.7%), dieticians (70.2%), nurses (66.7%), and physiotherapists (61.4%) were the most prevalent team members (Fig. 1B). Chest physicians, physiotherapists,

occupational therapists, social workers, psychologists and cardiologists were more frequent participants in Europe than North America. In North America, dieticians, exercise physiologists, and respiratory therapists were more common (Table).

Referral sources

Individuals with chronic respiratory disease were referred by a median of 2 referral sources (IQR: 2 to 3). Chest physicians and general practitioners were referring individuals with chronic respiratory disease to 95.3% and 73.3% of the pulmonary rehabilitation programs, respectively. Interestingly, self-referral was possible in 29.8% of the pulmonary rehabilitation programs (Fig. 2). It was more common for programs in North America to report referrals from general practitioners, self-referrals, or cardiologist than Europe (Table).

Patient volumes and completion rates

The respondents estimated that a total of 34,890 individuals with chronic respiratory disease enrolled in pulmonary rehabilitation programs in 2011 (median: 40 to 75 enrolled individuals per program; Fig. 3A). The median proportion of individuals with a chronic respiratory disease that completed a pulmonary rehabilitation program in 2011 was estimated to be between 75 to 90% (Fig. 3B). More patients were enrolled from Europe for 2011 than North America (Table).

Case mix

The case mix of individuals with chronic respiratory disease consisted of a median of 6 (IQR: 4 to 7) different primary diagnoses (Fig. 4A). Most pulmonary rehabilitation programs received referrals of individuals with 'stable' COPD (97.4% of the programs), COPD during and/or directly

following an exacerbation (74.9%), restrictive lung disease (including interstitial lung disease and thoracic wall diseases, 73.7%), asthma (71.9%), or post-thoracic surgery (71.9%) (Fig. 4B). Programs from North America reported more frequent referrals for restrictive lung disease, asthma and post-thoracic surgery than from Europe (Table).

Duration and frequency

The median length of the pulmonary rehabilitation programs was 9 weeks (IQR: 8 to 12 weeks). Individuals with a chronic respiratory disease attended a median of 2.5 pulmonary rehabilitation sessions per week (IQR: 2 to 3), for a median duration of 1.5 hours per session (IQR: 1 to 2). The median (IQR) number of hours of pulmonary rehabilitation dosage (number of weeks x number of sessions per week x number of hours per session) was similar for government funded programs (32 (IQR: 24 to 48) hours), insurance funded programs (36 (27 to 54) hours), or a combination thereof (36 (27 to 48) hours; p=0.31). Programs in North America were of longer in duration compared to European programs, while the number of sessions per week was greater and duration of sessions was longer for European programs. In turn, the total median hours of pulmonary rehabilitation dosage provided in Europe or North America was similar (Table).

Most important outcomes

Quality of life (82.1% of the respondents), 6-min walk test (45.8%), and dyspnea (41.4%) were identified as the three most important outcomes of pulmonary rehabilitation (Fig. 5). Quality of life remained one of the three most important outcomes after stratification for Europe or North America (Table). Programs in Europe reported on dyspnea and physical activity more commonly than North America. North America reported outcomes on the 6-min walk test, depression and

smoking cessation more frequently than Europe (Table), although neither continent reported on depression and smoking cessation frequently.

Interventions

The median number of types of interventions within the pulmonary rehabilitation programs was 11 (IQR: 9 to 12). The most common interventions were education (94.4% of the programs), stationary cycling (92.6%), breathing exercises including pursed lips breathing (91.6%), and nutritional support (84.4%) (Fig. 6). Outdoor walking and neuromuscular electrical stimulation were more commonly reported by programs in Europe, while treadmill walking, stationary cycling, resistance training with handheld weights, education, training in activities of daily living, self-management, nutritional support, breathing exercises and psychosocial support were more commonly reported in North America (Table). These differences however were not great. For example, 89.4% of programs in Europe reported on stationary cycling *versus* 97.3% in North America (Table).

DISCUSSION

This is the first global survey on content and organizational aspects of pulmonary rehabilitation. It was completed by representatives of 430 centres from 40 countries, and, as expected, the findings clearly show both key similarities as well as substantial differences between pulmonary rehabilitation programs across continents. The observed differences make (inter)national benchmarking difficult, and suggests caution in generalisation of research findings between such very different pulmonary rehabilitation programs.

Differences in content and organizational aspects

Pulmonary rehabilitation for individuals with chronic respiratory disease is recommended by national and international guidelines and statements (1, 20). The current findings show differences in each of the categories surveyed: the setting, the case-mix of individuals, the composition of the team, completion rates, methods of referral, and types of reimbursement. These findings corroborate previous reports performed at a national level (11, 14-17, 21).

An encouraging finding was the use of health-related quality of life as the primary outcome of programs, irrespective of jurisdiction. This reflects an evidence based approach to evaluating the most important endpoint of pulmonary rehabilitation. Unfortunately, the current survey did not allow us to identify which questionnaires are used to assess health-related quality of life in daily clinical practice. Nevertheless, multiple options are available (22). Approximately a third of programs employed measures of self-management as part of their primary outcomes, which, given the growing interest in self-management, especially around medication use and recognition of COPD exacerbations, is encouraging. Similarly, an awareness of the impact of pulmonary rehabilitation on activities of daily living was reflected by a number of programs in both major jurisdictions using it as an outcome. Just over half of the programs in North America utilize the 6-min walk test as a field measure of exercise capacity. Whereas this test is far less common in other parts of the world, the survey did not enable us to evaluate the frequency of alternative field tests such as the shuttle walk test, which has become more popular in the last decade (23). A small percentage of respondents included lung function as one of the three most important outcome measures for pulmonary rehabilitation. Such changes as might occur almost certainly reflect optimization of pharmacotherapy, which should occur prior to program enrolment. Disappointingly, few programs identified the important psychological secondary impairments of anxiety and depression as part of their primary outcome measures. Given the prevalence of these

symptoms and the positive impact that exercise has on them, increasing their use as outcome measures would be helpful (24, 25). The limited use of healthcare resource utilization (0.7%), despite clear evidence of the impact of rehabilitation on this outcome was also unfortunate as the latter provides powerful reasons in support of program funding related to significant reductions in healthcare costs among individuals with COPD (26). Longitudinal data collection of healthcare resource utilization currently most likely to occur primarily in academic programs should be encouraged for community and home based environments.

Patient satisfaction, and program's safety, efficiency, and accessibility were not identified as one of the top three most important outcomes of pulmonary rehabilitation. Even though this may not be recognized as important as performance metrics, it will provide detailed information about the pulmonary rehabilitation process. Moreover, healthcare facilities are increasingly being required to demonstrate these metrics as a condition of ongoing funding.

Case mix

The case mix of individuals with chronic respiratory diseases referred for pulmonary rehabilitation is highly variable, but indicates that the majority of the pulmonary rehabilitation programs, in addition to enrolling stable COPD patients, will also enrol individuals during or directly after a COPD exacerbation. Many also enrol individuals with a chronic respiratory disease other than COPD in keeping with the evolving scope of pulmonary rehabilitation (5, 9, 27-29). Obviously, the primary respiratory diagnosis (i.e., COPD) does not provide healthcare professionals with enough phenotypic information to come up with a patient-tailored pulmonary rehabilitation program. Therefore, a broad initial assessment is inevitable (30).

Pulmonary rehabilitation teams

An interdisciplinary pulmonary rehabilitation team should include physicians and skill sets associated with other healthcare professionals, such as physiotherapists, respiratory therapists, nurses, psychologists, behavioral specialist, exercise physiologists, nutritionists, occupational therapists, and social workers (1). The number and type of healthcare professionals varied amongst pulmonary rehabilitation programs (Fig. 1A and 1B) with physical therapists be especially popular in Europe, and respiratory therapists (who do not exist in Europe) dominating North American programs. In keeping with the interdisciplinary nature of pulmonary rehabilitation, available skill sets rather than specific healthcare professionals extends the program capability. It seems that some tasks are interchangeable with other healthcare professionals in daily clinical practice. For example, energy conservation techniques and/or activities of daily living training were available in 79.8% of the programs, while an occupational therapist was only available in 30.9% of programs.

Seventeen 'pulmonary rehabilitation teams' consisted of only one type of healthcare professional. This is somewhat surprising, as individuals with chronic respiratory disease can be very complex and need an integrated approach. Indeed, individuals with a chronic respiratory disease may present with multiple extra-pulmonary features and comorbidities, such as symptoms of anxiety and depression, body composition abnormalities, cognitive dysfunction, lower-limb muscle weakness, cardiovascular disease, and problematic activities of daily life (31-35). These extra-pulmonary features and comorbidities as well as poor self-management skills also need to be addressed during a comprehensive pulmonary rehabilitation program (36, 37). Indeed, many programs offered speciality components addressing extra-pulmonary features and/or comorbidities, e.g. 84.4% nutritional support, 79.8% energy conservation techniques and/or activities of daily living training, and 72.3% psychosocial support. Moreover, 80.0% of the programs offered self-management training, which is believed to be necessary to achieve a meaningful and sustainable behavior change (1).

International benchmarking

The observed differences in content and organizational aspects of pulmonary rehabilitation make benchmarking difficult among the various jurisdictions. Major differences in content and organization were identified between programs located in Europe and North America. It is unlikely that these differences are reported in clinical studies of rehabilitation and it is unknown as to whether variables such as team composition, skill mix, location and sources of payment have a direct impact on primary outcomes. Indeed, it is not clear whether extrapolating evidence from randomized controlled trials designed around a particular model of pulmonary rehabilitation may be generalized to other models.

The development of uniform performance and process metrics will enable more meaningful comparisons among programs in different jurisdictions. It will also allow quality control to ensure appropriate standards for pulmonary rehabilitation. As a result, international scientific groups, such as the ERS Group 01.02 ('Pulmonary Rehabilitation & Chronic Care'), ERS Group 09.02 ('Physiotherapy'), AACVPR, and the ATS Pulmonary Rehabilitation Assembly would greatly benefit from discussing future steps on how to compare the processes and results of other pulmonary rehabilitation programs to one's own results. An international benchmarking approach could even be used to set aspirational targets. Obviously, the number of performance and process metrics need to be limited to keep things manageable (38). However, a performance dashboard which produces reports easily using standardized metrics can generate insights between performance and process metrics that are currently lacking in the field of pulmonary rehabilitation.

Methodological limitations

Although the total number of pulmonary rehabilitation programs present world-wide is unknown, it is undoubtedly substantially greater than 430. Therefore, we acknowledge that, since many pulmonary rehabilitation programs did not share their details, our study results may be subject to selection bias. We believe some of the reasons behind non-response to our inquiry may have been that some healthcare professionals involved in pulmonary rehabilitation were not proficient in English (especially in Asia, South America and Africa); some were not aware of this survey; or some were too busy to reply. Therefore, the current findings must be considered hypothesis-generating rather than definitive. Based on the current findings, it is not possible to ascertain whether regional differences in pulmonary rehabilitation programs are due to genuine differences in approach to pulmonary rehabilitation, health inequalities, differences in local healthcare systems, or other unrecognized factors. Nevertheless, this survey can be seen as the first step towards a possible future uniformity concerning performance and process metrics in pulmonary rehabilitation.

In conclusion, large differences exist in content and organizational aspects among pulmonary rehabilitation programs worldwide. The current findings stress the importance of future development of process and performance metrics to monitor pulmonary rehabilitation programs, to be able to start international benchmarking, and to provide recommendations for international standards based on evidence and best practice. Differences in content and organizational aspects of pulmonary rehabilitation programs suggest caution in generalisation of research findings.

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COMPETING INTERESTS

None declared.

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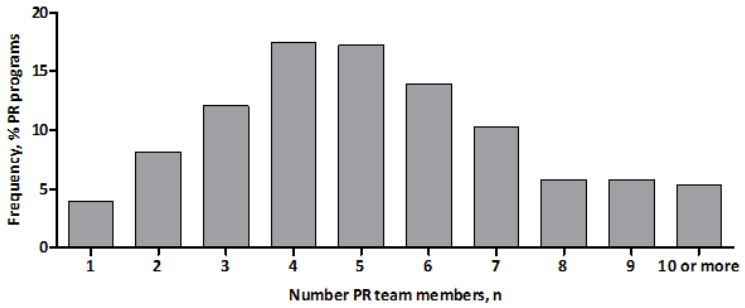
FIGURE LEGENDS

Figure 1A

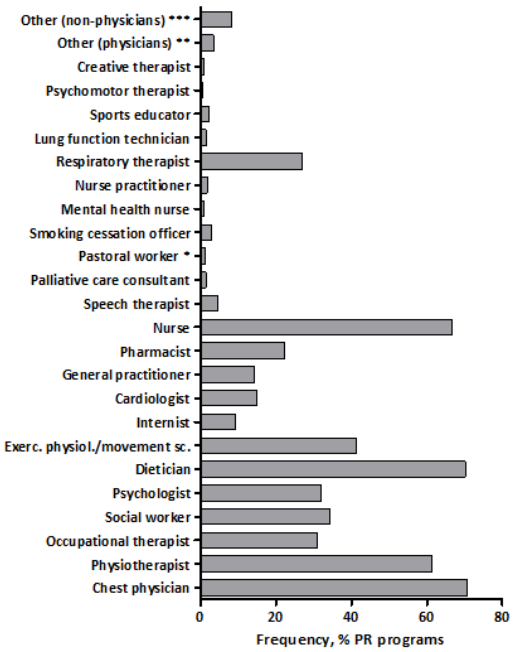
Figure 1A. Number of team members



PR: pulmonary rehabilitation

Figure 1B

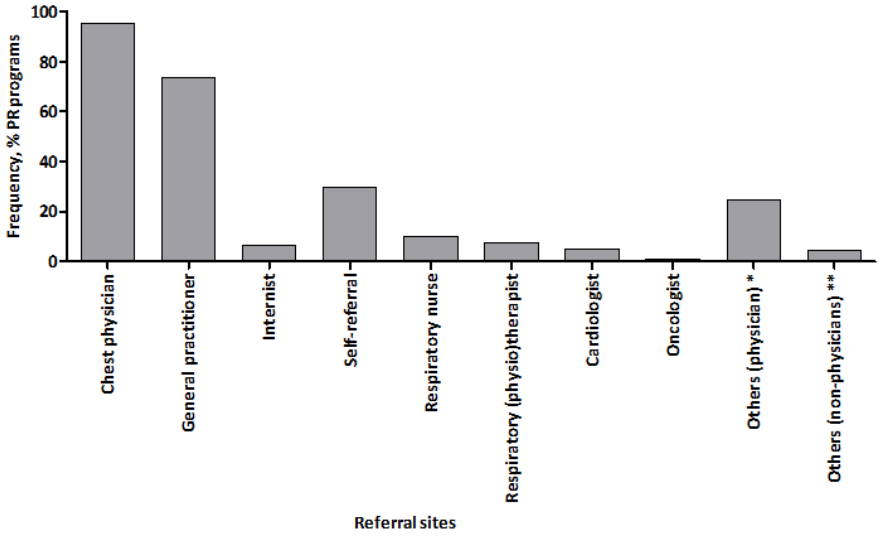
Figure 1B. Frequency of healthcare professionals



PR: pulmonary rehabilitation; *: includes, but not limited to: chaplain, parish nurse and pastoral worker; **: includes, but not limited to: geriatrician, neurologist, physiatrist, rheumatologist, surgeon, and endocrinologist; ***: includes, but not limited to: citizens advisor, volunteers, welfare right advisor, council development worker, lung foundation support representative, dental hygienist, diabetes educators, and alternative medicine practitioner.

Figure 2

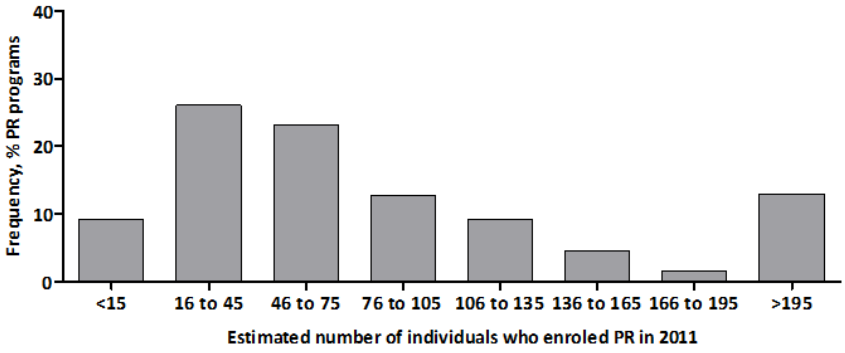
Figure 2. Referral sites



PR: pulmonary rehabilitation; *: includes, but not limited to: physiatrist, surgeon, 'medical staff', 'hospitalist', geriatrician, and paediatrician; **: includes, but not limited to: waiting list from other pulmonary rehabilitation program, community staff, occupational therapy, personal trainer, lung foundation, and nutritionist.

Figure 3A

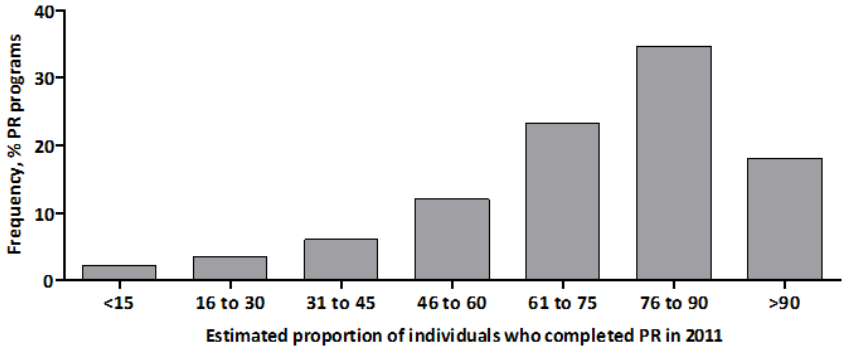
Figure 3A. Enrolment numbers



PR: pulmonary rehabilitation

Figure 3B

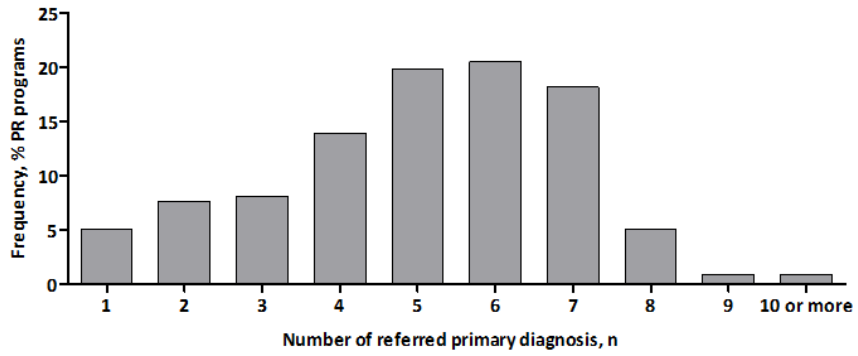
Figure 3B. Completion numbers



PR: pulmonary rehabilitation

Figure 4A

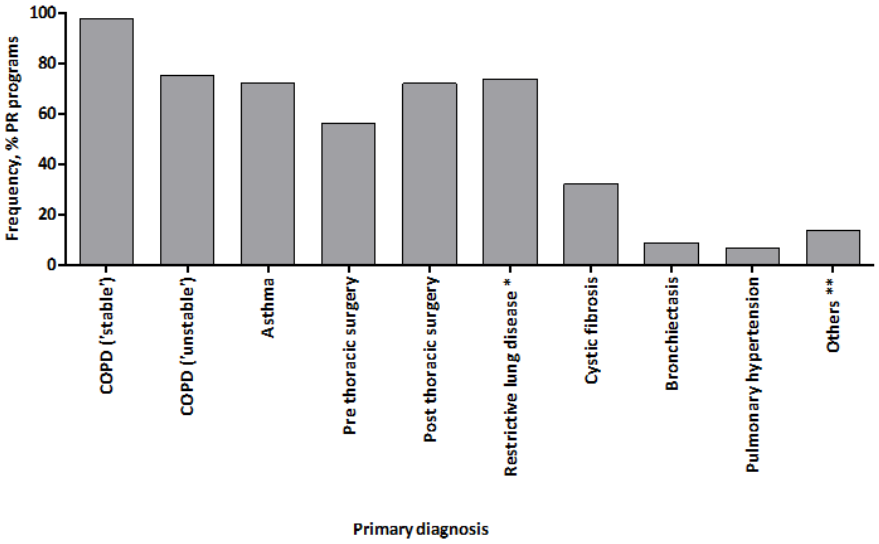
Figure 4A. Number of primary diagnosis



PR: pulmonary rehabilitation

Figure 4B

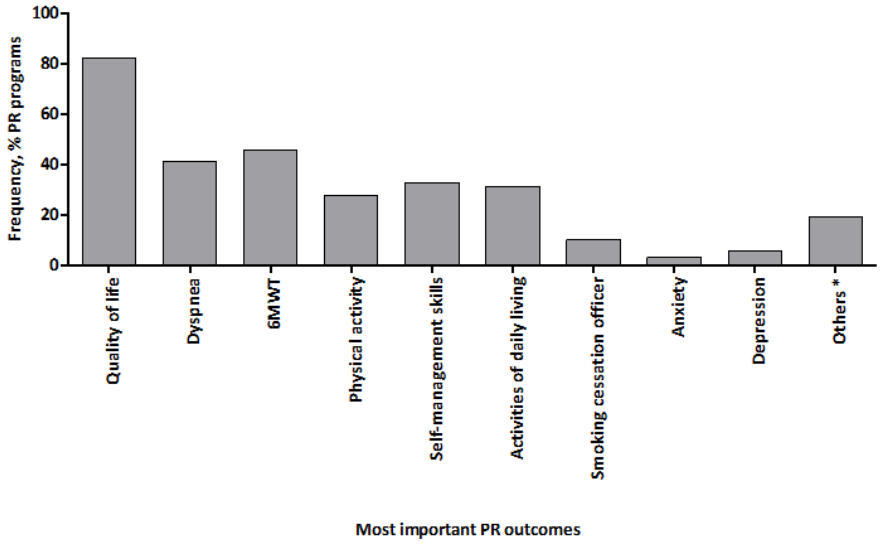
Figure 4B. Frequency of primary diagnosis



PR: pulmonary rehabilitation; *: includes, but not limited to: interstitial lung disease, like sarcoidosis and idiopathic pulmonary fibrosis, and chest wall disease, like kyphoscoliosis; **: includes, but not limited to: neuromuscular disease, diaphragm paresis, hyperventilation, chronic heart failure, post intensive care unit, obesity, pre-bariatric surgery, and post-bone marrow transplantation.

Figure 5

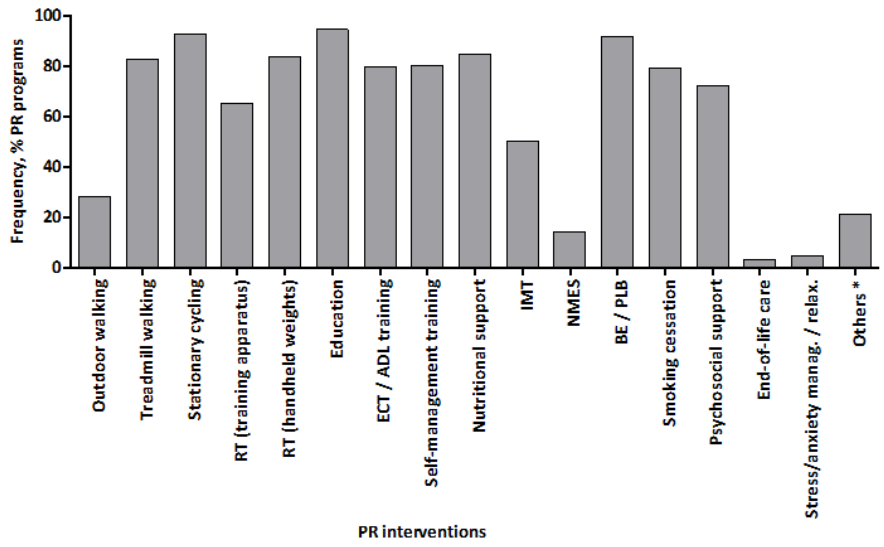
Figure 5. Most important outcomes



PR: pulmonary rehabilitation; * includes, but not limited to: lung function, body composition, drug use, shuttle walk test, lower-limb muscle strength, upper limb muscle strength, and patient goals.

Figure 6

Figure 6. Types of interventions



PR: pulmonary rehabilitation; RT: resistance training; ECT: energy conservation techniques; ADL: activities of daily life; IMT: inspiratory muscle training; NMES: neuromuscular electrical stimulation; BE: breathing exercise; PLB: pursed lips breathing; *: includes, but not limited to: other types of physical exercise training, goal setting, airway clearance techniques, water therapy, psychomotor therapy, enhanced art therapy, arm cranking, and support group.