

This is a repository copy of *Patients' perspective on pulmonary rehabilitation: experiences of European and American individuals with chronic respiratory diseases*.

White Rose Research Online URL for this paper:
<https://eprints.whiterose.ac.uk/157008/>

Version: Published Version

Article:

Rochester, Carolyn, Vogiatzis, Ioannis, Powell, Pippa et al. (2 more authors) (2018)
Patients' perspective on pulmonary rehabilitation: experiences of European and American individuals with chronic respiratory diseases. ERJ open research. pp. 1-4. ISSN 2312-0541

<https://doi.org/10.1183/23120541.00085-2018>

Reuse

This article is distributed under the terms of the Creative Commons Attribution-NonCommercial (CC BY-NC) licence. This licence allows you to remix, tweak, and build upon this work non-commercially, and any new works must also acknowledge the authors and be non-commercial. You don't have to license any derivative works on the same terms. More information and the full terms of the licence here:
<https://creativecommons.org/licenses/>

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



Patients' perspective on pulmonary rehabilitation: experiences of European and American individuals with chronic respiratory diseases

To the Editor:

Despite the fact that pulmonary rehabilitation (PR) is the most powerful nonpharmacological intervention to improve the symptoms, exercise capacity and quality of life of people living with chronic lung disease [1], fewer than 2% of eligible patients enrol [2, 3]. While preparing a joint American Thoracic Society (ATS)/European Respiratory Society (ERS) Policy Statement on pulmonary rehabilitation [4], we developed a survey to better understand patients' perspectives on PR, and to identify challenges faced both by patients who have taken part in PR and those who might be eligible but have not had the opportunity. The survey was disseminated *via* the European Lung Foundation/ERS and ATS Public Advisory Roundtable professional patient networks, and *via* the COPD Foundation and Pulmonary Fibrosis Foundation to patients with a wide range of chronic lung diseases. The survey was available online from July, 2014 to November, 2014 in 10 languages (Dutch, English, Flemish, French, German, Greek, Italian, Polish, Portuguese and Spanish). Responses were received from 1685 people (73% female) with self-reported chronic lung disease in 29 countries (USA: 71.1%; Europe: 27.4%; others: 1.5%) and were included in the analyses (table 1).

A majority of patients were 61 years of age or older (54.7%). 92% of respondents thought that PR should be a part of healthcare services available to all patients that might benefit, yet 46% of respondents had never taken part in a PR programme. 60% reported having experienced challenges to taking part in PR (table 1). Approximately two-fifths of respondents reported that their healthcare provider had never told them about PR, or the benefits of PR for people living with chronic lung disease. 18% felt they did not have enough information to decide about participating or were not sure it would help them. Nearly one-fifth of respondents faced logistical challenges, such as no PR service available or lack of insurance coverage. Emotional challenges were also an obstacle to participation.

Of the respondents who had participated in PR, most had heard about it through their healthcare provider (table 1). A majority of these individuals reported improvements in physical functioning in daily life, mood or sense of emotional wellbeing, knowledge about their lung condition, control of symptoms, social functioning, or a combination thereof (table 1). PR participants were asked to respond to the question "What would you say to someone considering attending a PR session for the first time?". Representative responses included: "Absolutely do it!", "A must!", "It allows you to move around and breathe better", "Absolutely go all in!", "Be open about your symptoms and condition", "Begin as soon as possible", "Best thing I ever did to help manage this disease", "Don't be a damn fool – go and help yourself", "Don't be scared", "It will change your life", and "It works!". None of the respondents made negative comments or recommended against participation in PR. Patients who had participated also offered suggestions as to how to improve the PR experience. Representative suggestions included having PR facilities closer to home, having appropriate funding and lower "out of pocket" costs, a longer duration of PR programme or the opportunity to do two PR programmes per year, opportunity to transition to a maintenance



@ERSpublications

Pulmonary rehabilitation benefits people with chronic respiratory diseases, yet few eligible patients enrol. People with chronic lung diseases are often unaware of or lack access to PR. This is an important healthcare disparity that should be addressed. <http://ow.ly/2HER30mxLLj>

Cite this article as: Rochester CL, Vogiatzis I, Powell P, *et al.* Patients' perspective on pulmonary rehabilitation: experiences of European and American individuals with chronic respiratory diseases. *ERJ Open Res* 2018; 4: 00085-2018 [<https://doi.org/10.1183/23120541.00085-2018>].

Copyright ©ERS 2018. This article is open access and distributed under the terms of the Creative Commons Attribution Non-Commercial Licence 4.0.



TABLE 1 Patient survey on experiences relating to pulmonary rehabilitation (PR)

Total number of respondents n	1685
What is your age group?	
18–30 years	24 (1.4)
31–50 years	287 (17.0)
51–60 years	452 (26.8)
61–70 years	520 (31.4)
>70 years	393 (23.3)
Not reported	9 (0.1)
Gender	
Women	1229 (72.9)
Men	450 (26.7)
Not reported	6 (0.4)
Have you ever been told about PR by your healthcare provider?	
Yes	1009 (59.9)
No	614 (36.4)
Not sure	62 (3.7)
Has a healthcare provider ever discussed the benefits of PR with you?	
Yes	939 (55.7)
No	702 (41.7)
Not sure	41 (2.4)
Not reported	3 (0.2)
Have you ever taken part in PR?	
Yes	904 (53.6)
No	770 (45.7)
Not sure	10 (0.6)
Not reported	1 (0.1)
If you have taken part in PR, how did you hear about it? You can choose more than one option.	
Healthcare provider	807 (89.3)
On the internet	74 (8.2)
Published literature, such as newspapers or academic journals	46 (5.1)
Pamphlet/flyer	30 (3.3)
Advertisement (on TV, radio or in a magazine)	5 (0.6)
A friend or a family member	69 (7.6)
Someone who had taken part in PR	109 (12.1)
If you have taken part in PR, did you....?	
Complete the whole programme	777 (86.0)
Stop early	98 (10.8)
Not reported	29 (3.2)
Reasons for stopping early (if applicable) (individual patient responses below):	
Medical comorbidities/accident	
Costs of the PR programme	
Exacerbation of chronic lung disease	
Death in the family	
Still actively participating in the PR programme	
If you have participated in PR, what is the lung condition for which you were referred?	
COPD	495 (54.8)
Pulmonary fibrosis (or interstitial lung disease)	201 (22.2)
Pulmonary hypertension	56 (6.2)
Asthma	41 (4.5)
Cystic fibrosis	12 (1.3)
Bronchiectasis	15 (1.7)
Lung cancer	14 (1.6)
Other (including but not limited to) (individual patient responses below):	70 (7.7)
After pneumonia	
α_1 -antitrypsin deficiency	
Chronic bronchitis	
After lung transplantation	
Do you think that PR should be a part of healthcare services available to all patients that might benefit from it?	
Yes	1549 (91.9)
No	3 (0.2)
Not sure	111 (6.6)
Not reported	22 (1.3)

Continued

TABLE 1 Continued

Have you experienced any challenges to taking part in PR? (Multiple answers possible.)	
No challenges	670 (39.8)
Never heard of PR	377 (22.4)
Not enough information to decide whether I want to participate	162 (9.6)
Not sure whether it would help me	150 (8.9)
Worried it might be painful	37 (2.2)
There is no PR service in my area	134 (8.0)
The doctor did not think it would help me	44 (2.6)
Did not qualify for the service in my area	38 (2.3)
Cannot get to the appointments, because the service is too far away	52 (3.1)
Not covered by my insurance	93 (5.5)
Lack of encouragement from the people running the program/staff	45 (2.7)
Family not supportive	19 (1.1)
Low self-confidence or anxiety	72 (4.3)
Other (including, but not limited to) (individual patient responses below):	247 (14.7)
Medical comorbidities	
Disease instability/frequent exacerbations	
Inconvenient PR times (still working/need for childcare)	
PR programme (initially) limited to COPD patients only	
Poor/no PR facilities available	
Exercising with people on oxygen supplements was detrimental	
No/pending approval from insurance	
Lack of clarity in the referral process and reimbursement	
[Co-]pay is too expensive	
Transportation problems	
Patient believes to be too ill to participate in PR	
Patients believes to be active enough/PR not necessary	
Physician unknown with the effects of PR	
If you have participated in PR, what do you feel were the major benefits of the programme for you? You can choose more than one option.	
Improved physical functioning in daily life	658 (75.8)
Improved mood or sense of emotional wellbeing	439 (48.6)
Improved knowledge about lung condition	474 (52.4)
Improved control of symptoms	416 (46.0)
Improved social functioning	261 (28.9)
Other (including but not limited to) (individual patient responses below):	277 (30.6)
A combination of the abovementioned improvements	
Improved quality of life	
Improved mobility	
Empowering	
Improved lifestyle	
Improved self-confidence	
Improved understanding of my problems	
No change/improvement	

Data are presented as n (%), unless otherwise stated. COPD: chronic obstructive pulmonary disease.

programme, having the option for PR sessions during evenings or the weekend days, addition of yoga and/or meditation to the PR programme, and the importance of individualisation of the PR programme to each patient's condition (including the educational component and need for staff to have knowledge of respiratory disorders other than chronic obstructive pulmonary disease (COPD)). Notably, three-fifths of respondents reported that they experienced one or more challenges to taking part in PR.

In 2015, the official ATS/ERS policy statement on enhancing implementation, use and delivery of pulmonary rehabilitation highlighted the need to increase patients' and healthcare providers' awareness and knowledge of PR, as well as to increase patients' access to PR [4]. For example, it was recommended that professional societies and patient advocacy and education experts develop education materials for people living with chronic respiratory disease regarding the process and benefits of PR. Public awareness campaigns are also needed. The current survey data confirms the need for greater healthcare professionals' knowledge and awareness of PR to foster patient referrals, and for new PR services to reduce travel

distance and transportation problems, for increased insurance coverage for PR, and expanded PR services that do not focus solely on COPD.

Our survey-based study has some limitations. Given that the majority of respondents were from Europe and North America, the generalisability of our findings to other first world and/or developing countries is unknown. Moreover, the participation and engagement of many of our respondents in patient networks and health societies might have introduced bias into the survey findings, since these individuals may have been especially motivated to take control of and manage their respiratory disease. Future efforts to learn more about the perspectives of individuals from other countries underrepresented in the present survey, and those not engaged in patient networks or health societies would be both informative and beneficial.

In keeping with the ATS/ERS policy statement on PR [4], however, this survey demonstrates clearly that people with chronic lung diseases in Europe and the USA want to learn about and be able to participate in PR, yet are often unaware of it, its benefits or lack access to it. Importantly, these findings are probably “the tip of the iceberg”, since only people with computer and internet access could respond to this survey. Referrals, access to and uptake of PR are likely significantly further diminished among those from more remote, under-served or poverty-stricken areas [5]. We believe this is an important healthcare disparity that should be addressed by healthcare providers and health systems in the years to come.

Carolyn L. Rochester^{1,2,9}, Ioannis Vogiatzis^{3,4,9}, Pippa Powell⁵, Sarah Masefield⁵ and Martijn A. Spruit^{6,7,8}

¹Section of Pulmonary, Critical Care and Sleep Medicine, Yale University School of Medicine, New Haven, CT, USA. ²VA Connecticut Healthcare System, West Haven, CT, USA. ³National and Kapodistrian University of Athens, Faculty of Physical Education and Sports Sciences, Athens, Greece. ⁴Dept of Sport, Exercise and Rehabilitation, School of Health and Life Sciences, Northumbria University Newcastle, Newcastle Upon Tyne, UK. ⁵European Lung Foundation, Sheffield, UK. ⁶Dept of Research and Education, CIRO+, Center of Expertise for Chronic Organ Failure, Horn, The Netherlands. ⁷Dept of Respiratory Medicine, Maastricht University Medical Centre, NUTRIM School of Nutrition and Translational Research in Metabolism, Maastricht, The Netherlands. ⁸REVAL - Rehabilitation Research Center, BIOMED - Biomedical Research Institute, Faculty of Rehabilitation Sciences, Hasselt University, Diepenbeek, Belgium. ⁹Both authors contributed equally.

Correspondence: Carolyn L. Rochester, Section of Pulmonary, Critical Care and Sleep Medicine, Yale University School of Medicine, 333 Cedar Street, BLDG LCI-105, New Haven, CT 06520, USA.
E-mail: carolyn.rochester@yale.edu

Received: June 11 2018 | Accepted after revision: Oct 19 2018

Author contributions: Each of the authors listed played an essential role in the development of the patient survey, analysis of the findings, and development of this manuscript.

Conflict of interest: Carolyn L. Rochester has served on scientific advisory boards for COPD for Glaxo-Smith Kline, Inc, and Boehringer Ingelheim Pharmaceuticals, Inc. She has participated in COPD-related clinical trials sponsored by GSK and Astra-Zeneca Pharmaceuticals, Inc. Carolyn L. Rochester co-chaired the ATS-ERS joint task force on policy in pulmonary rehabilitation, and from 2015–2017 served as the chair of the ATS Assembly on pulmonary rehabilitation. She does not believe any of the above represent conflicts of interest in regard to the currently submitted research letter. I. Vogiatzis has nothing to disclose. P. Powell is an employee of the European Lung Foundation. S. Masefield was an employee of the European Lung Foundation at the time of writing. M.A. Spruit reports personal fees from Boehringer Ingelheim, GSK and AstraZeneca, and grants from Netherlands Lung Foundation, outside the submitted work.

Support statement: This patient survey was funded by the American Thoracic Society and European Respiratory Society. Funding information for this article has been deposited with the Crossref Funder Registry.

References

- 1 Spruit MA, Singh SJ, Garvey C, *et al.* An official American Thoracic Society/European Respiratory Society statement: key concepts and advances in pulmonary rehabilitation. *Am J Respir Crit Care Med* 2013; 188: e13–e64.
- 2 Brooks D, Sottana R, Bell B, *et al.* Characterization of pulmonary rehabilitation programs in Canada in 2005. *Can Respir J* 2007; 14: 87–92.
- 3 Wadell K, Janaudis Ferreira T, Arne M, *et al.* Hospital-based pulmonary rehabilitation in patients with COPD in Sweden—a national survey. *Respir Med* 2013; 107: 1195–1200.
- 4 Rochester CL, Vogiatzis I, Holland AE, *et al.* An official American Thoracic Society/European Respiratory Society policy statement: enhancing implementation, use, and delivery of pulmonary rehabilitation. *Am J Respir Crit Care Med* 2015; 192: 1373–1386.
- 5 Johnston KN, Williams MT. Turning a challenge into an opportunity: pulmonary rehabilitation and socioeconomic deprivation. *Thorax* 2017; 72: 493–494.