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

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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

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| 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              |      |
| α1-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) |
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

### TABLE 1

| 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.
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.

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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 and Astra-Zeneca Pharmaceuticals. 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.

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