

# 'Tired, afraid, breathless . . .' An international survey of the exercise experience for people living with pulmonary hypertension

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## Abstract

Patients with pulmonary hypertension are more sedentary than the general population, but attitudes and experiences that may influence their exercise behaviour remain poorly understood. This study identified patterns of behaviour, attitudes towards exercise, barriers and enablers of exercise for people living with pulmonary hypertension. Accessibility of rehabilitation services from a patient perspective was also explored. A voluntary, international survey of people living with pulmonary hypertension was conducted, with mixed quantitative and qualitative data collection. Data from 187 participants in 19 countries were included in the analyses. In total, 52% (95/183) of people with pulmonary hypertension reported that they attempted to engage in regular physical activity. This was less than the proportion who did so prior to diagnosis (61%, 112/184,  $p=0.006$ ) and was accompanied by uncertainty and anxiety about exercise. In total, 63% (113/180) of the cohort reported experiencing previous adverse events while exercising, which was associated with a greater likelihood of ongoing exercise concerns and anxiety. Fear, frustration and uncertainty about exercise were noted as common barriers to engaging in exercise with pulmonary hypertension. Other barriers to exercise included intrinsic factors such as debilitating breathlessness and fatigue, and external factors such as cost and access to appropriate services. Most respondents (76%, 128/169) did not have access to a multi-disciplinary rehabilitation service, although an overwhelming majority (92%, 159/172) reported that this would be helpful. Respondents rated education; a supervised, structured exercise programme; and psychology input as the most important components of a multi-disciplinary rehabilitation service for pulmonary hypertension. Health professionals must work together with consumers to co-design rehabilitation services that will facilitate exercise and increased activity for people living with pulmonary hypertension.

## Keywords

exercise, rehabilitation, pulmonary hypertension, cardiopulmonary, qualitative, barriers

Date received: 16 July 2020; accepted: 30 September 2020

Pulmonary Circulation 2020; 10(4) 1–10

DOI: 10.1177/2045894020968023

## Introduction

Pulmonary hypertension (PH) is a progressive, disabling condition of the pulmonary vasculature associated with significant morbidity and mortality.<sup>1</sup> The global prevalence of PH is approximately 1%, increasing up to 10% for those  $\geq 65$  years of age.<sup>2</sup> PH is classified into five main clinical groups: pulmonary arterial hypertension (PAH); PH due to left heart disease; PH related to lung disease; chronic

thromboembolic pulmonary hypertension (CTEPH); and PH of unknown aetiology.<sup>3</sup> Previously, exercise was not recommended for patients with PH due to safety concerns.<sup>4</sup> However, exercise training has been shown to safely

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improve exercise capacity and quality of life in patients with PH and is now recommended in clinical guidelines.<sup>5</sup> Despite this, patients with PH are known to be more sedentary and report reduced quality of life compared to age- and gender-matched controls.<sup>6–9</sup>

Several studies have used activity monitoring devices to quantify physical activity in patients with PH, including measurement of metabolic equivalents (METs).<sup>10</sup> Patients with idiopathic PAH were seen to have lower mean daily step counts, daily energy expenditures and reduced duration of moderate physical activities (classified as >3 METs) compared to controls.<sup>6</sup> Patients with PAH were observed to spend up to 92.1% of their average day in sedentary behaviour, significantly more than controls ( $p < 0.001$ ).<sup>7</sup> These low activity levels in patients with PAH have been associated with self-reported fatigue.<sup>8</sup>

It remains unclear why people living with PH are sedentary. Few studies have explored the patient experience of exercise, nor specific barriers and enablers of exercise that might be experienced by people living with PH. This study sought to address gaps in our understanding of the attitudes, beliefs and experience of exercise among patients with PH.

Specifically, this study aimed to:

- (i) explore exercise behaviour and attitudes towards exercise;
- (ii) identify perceived barriers and enablers of exercise; and
- (iii) assess the accessibility of rehabilitation services for people living with PH.

## Methods

### Study design and participants

A cross-sectional English language survey was designed in accordance with The Checklist for Reporting Results of Internet E-surveys (CHERRIES)<sup>11</sup> to assess exercise attitudes and behaviours in people who self-identified as having PH. Eligible participants were people who identified as having a diagnosis of PH (of any aetiology), aged at least 18 years of age and able to communicate in English.

The survey comprised of 30 items assessing participant demography (such as age, gender, type of PH, current employment status, country of residence and education level); patterns of exercise behaviour before/after PH diagnosis; and perceived attitudes towards exercise. The survey also scoped exercise beliefs and practices; concerns about exercise; the importance and safety of exercise; perceived barriers and enablers of exercise from the consumer perspective; current access to PH-specific exercise and rehabilitation services; and the perceived need for various exercise and rehabilitation supports from people living with PH.

The survey was designed by the authors to be voluntary, anonymous and suitable for international dissemination.

The survey questions and list of barrier and enabler response options were developed based on author consensus (clinical experience in cardiac and pulmonary rehabilitation and acute PH management); review of the available literature to date; and consumer feedback from people living with PH. After an initial list was developed by the authors, it was piloted with PH consumers, whose input was used to refine the final list included in the questionnaire.

Most survey questions were dichotomous or categorical, requiring selection from a list of fixed response options, with simple logic used to elicit more detail where applicable. A number of open-ended questions with free-text response fields were also included. Prior to dissemination, the survey was piloted in Australia by a small group of consumers with PH ( $n = 5$ ) and endorsed by the Pulmonary Hypertension Association of Australia (PHAA), a major PH support group in Australia. The study was approved by the Human Research Ethics Committee of our Hospital. (2018/ETH00430).

### Survey dissemination and data collection

The survey was made available in both paper-based and electronic format, via the secure, web-based electronic data capture system, Research Electronic Data Capture (REDCap).<sup>12,13</sup> Online respondents provided electronic consent prior to survey completion, while paper-based respondents were advised that submission of the survey indicated their consent. No incentives were given to participate, and no identifiable participant data were collected.

Participants were recruited either online or in-person, via attendance at:

- an outpatient Heart Failure or Pulmonary Hypertension Clinic, in a PH specialist centre in Australia or
- an annual patient support group meeting of the PHAA. A member of the research team (K.S.W.C., K.B.) was present at each meeting to explain the study to potential participants and invite them to participate.

Online advertisement via web-based platforms was used to disseminate the survey internationally, including social media platforms Twitter<sup>TM</sup>, LinkedIn<sup>TM</sup>, Facebook<sup>TM</sup> and hospital websites. A variety of established international PH patient support groups were contacted directly via email to inform them of the study, including PH support associations of Australia, the USA, Canada, Latin America, the United Kingdom (UK), Ireland, Europe, Denmark, Norway, Sweden, Finland, Germany, France, Italy, Greece, Spain, Poland, Slovakia, Japan, Korea, Singapore and China. These groups were invited to review study documentation and disseminate study information and the survey link to their members, at their discretion. Survey responses were collected over a 12-month period (January 2019 to January 2020). Data were managed via REDCap,<sup>12,13</sup> at our Hospital.

## Data analyses

Participants who provided valid responses to any part of the survey were included in the analyses. Quantitative data were collated and analysed using SPSS (version 26, Armonk, NY, USA). Descriptive statistics were used to summarise the cohort and quantitative responses. Non-parametric statistical methods were used for ordinal data collected via Likert scales. Chi-squared analyses were used to compare dichotomous variables, while Wilcoxon-signed rank tests were used to compare paired ordinal variables. Friedman's analyses of variance were used to perform statistical comparisons of three or more ordinal variables; namely, to compare the perceived importance of five related features of a rehabilitation service. Post hoc between-group comparisons were performed via Wilcoxon-signed rank tests, with a Bonferroni correction applied resulting in an adjusted significance threshold of  $p < 0.005$  for this particular analysis. Quantitative data are reported as number (percent) and median [interquartile range] throughout the manuscript, and results were considered significant where  $p < 0.05$  (unless otherwise stated).

Qualitative free-text responses were extracted and analysed thematically using NVivo software (version 12, QSR International, (1999) NVivo Qualitative Data Analysis Software). Data were reviewed and coded according to emergent themes in the data, related to exercise attitudes/beliefs; perceived barriers to exercise; and perceived enablers of exercise. Major themes and exemplar quotes are presented throughout the results.

## Results

A total of 202 people responded to the survey. Fifteen respondents (all online) provided no demographic data and were excluded, leaving 187 participants included in the analyses. Paper responses were received from 84 participants (45%), and the remaining 103 (55%) responded online.

*Response rates:* a total of 214 paper surveys were handed out. The response rate for paper surveys was 39% (84/214). Unfortunately, we were unable to determine the size of the online source population. Participants from 19 different countries were represented, most commonly from Australia and New Zealand (109/178, 61%), followed by the USA (30/178, 17%). Full demographic details for the participant cohort are presented in Table 1.

### Perceived importance and benefits of exercise

The importance of exercise for the general population was rated by 90% of respondents as 'essential' or 'very important' (167/185); 8% were uncertain (15/185) and 1.6% believed exercise to be of 'little importance' (3/185). Reasons cited in free-text responses included physical benefits and positive impacts on mental health and well-being: 'exercise is good for well being, feeling positive,

**Table 1.** Participant demographics.

Variable	Number (%) (total possible $n = 187$ )
<b>Age (years)</b>	<b><math>n = 187</math></b>
18–24	5 (3)
25–30	11 (6)
31–40	31 (17)
41–50	41 (22)
51–60	42 (22)
61–70	33 (18)
71–80	21 (11)
> 80	3 (2)
<b>Gender</b>	<b><math>n = 183</math></b>
Male	21 (11)
Female	162 (89)
<b>Location of respondent</b>	<b><math>n = 178</math></b>
Australia and New Zealand	109 (61)
United States of America	30 (17)
Scandinavia	14 (8)
Europe	13 (7)
Singapore and Malaysia	5 (3)
South America	4 (2)
United Kingdom and Ireland	3 (2)
<b>Rurality<sup>a</sup> of place of residence</b>	<b><math>n = 182</math></b>
Urban	114 (63)
Regional/rural	68 (37)
<b>Pulmonary hypertension (PH) type</b>	<b><math>n = 185</math></b>
Group 1 (pulmonary arterial hypertension)	150 (81)
Group 2 (PH due to left heart disease)	7 (4)
Group 3 (PH due to lung disease)	4 (2)
Group 4 (chronic thromboembolic PH)	12 (6)
Group 5 (other)	1 (0.01)
Don't know	11 (6)
<b>Years since PH diagnosis</b>	<b><math>n = 182</math></b>
0–1	23 (13)
2–4	45 (25)
5–7	20 (11)
8–10	30 (16)
> 10	60 (33)
Don't know	4 (2)
<b>Highest level of education</b>	<b><math>n = 185</math></b>
Primary school	6 (3)
Secondary school	60 (32)
TAFE <sup>b</sup> /diploma/vocational	42 (23)
University undergraduate	39 (21)
University postgraduate	38 (21)
<b>Current employment status</b>	<b><math>n = 185</math></b>
Student	3 (2)
Employed	63 (34)

(continued)

**Table 1.** Continued.

Variable	Number (%) (total possible <i>n</i> = 187)
Unemployed	45 (24)
Retired	74 (40)
<b>Pulmonary hypertension support group</b>	(some respondents belonged to > 1 group)
PHAA	61
PHA US	40
PHA UK	15
PHA Europe	11
Other support group (including PH Singapore, PH Norway, PH India, Facebook support group, other unspecified)	36
Not a member of any support group	71

PHAA, Pulmonary Hypertension Association of Australia; PHA US, Pulmonary Hypertension Association of the United States; PHA UK, Pulmonary Hypertension Association of the United Kingdom; PHA Europe, Pulmonary Hypertension Association of Europe.

<sup>a</sup>Rurality: urban was defined as a major city with population > 100,000; rural or remote was defined as population < 100,000; in accordance with Australian Government Remoteness Classification (Health 2008).

<sup>b</sup>TAFE: Technical and Further Education, Australia.

independence, it keeps you healthy and strong'. Other physiological benefits of exercise were also noted, such as improvements in general health, immunity and reductions in cholesterol.

Respondents rated exercise as less important for those with PH than for the general population ( $z = -3.9$ ,  $p < 0.001$ ). Overall, 74% of respondents (137/185) perceived exercise as 'essential' or 'very important' for patients with PH (compared to 90% for the general population); while 22% were uncertain (40/185), and 4% (8/185) rated exercise to be of 'little importance'.

For those who rated exercise as of 'little importance' or 'uncertain' for the general population ( $n = 15$ ), 10/15 also rated exercise as of 'little importance' or 'uncertain' for PH specifically; reflecting attitudes to exercise generally. However, four participants who rated exercise as of 'little importance' or 'uncertain' for the general population noted in contrast that it was 'very important' for people with PH. Reasons given were that exercise would help the respondent to 'be less of a burden'; the knowledge that 'weight contributed to my PH'; and direct advice to exercise 'I have been told so'.

A higher proportion of respondents were uncertain about the importance of exercise for people with PH, compared to the general population (21% uncertain, versus 8%). Respondents expressed uncertainty about the safety of exercise for PH (6% coverage in Nvivo free-text analysis): 'I'm not sure if activity puts additional strain on the heart... are there risks? Sometimes I worry I am doing too much and

**Table 2.** Exercise behaviour of participants before and after diagnosis with pulmonary hypertension.

	Prior to diagnosis ( <i>n</i> = 182)	In the past week ( <i>n</i> = 182)
<b>Typical amount of exercise per week (h)</b>	<b><i>n</i> (%)</b>	<b><i>n</i> (%)</b>
None	71 (39)	87 (48)
<1	8 (4)	20 (11)
1–2	23 (13)	18 (10)
2–3	16 (9)	16 (9)
3–4	17 (9)	9 (5)
4–5	20 (11)	12 (7)
>5	26 (14)	17 (9)
unspecified amount	1 (0.01)	3 (0.02)
<b>Type of regular exercise performed<sup>a</sup></b>		
Walking	90 (49)	81 (45)
Running	25 (14)	4 (2)
Swimming	32 (18)	13 (7)
Cycling	16 (9)	16 (9)
Gym/personal trainer	38 (21)	23 (13)
Weights/resistance training	13 (7)	15 (8)
Yoga/Pilates	18 (10)	15 (8)
Other <sup>b</sup>	25 (14)	15 (8)

<sup>a</sup>Some respondents performed more than one type of exercise; therefore, total number of responses was greater than the number of participants.

<sup>b</sup>Included aqua aerobics, golf, recumbent stepper, dance classes, outdoor work, croquet, tennis and rehabilitation classes.

could damage my heart'. There was also uncertainty about suitable exercise: 'I'm not sure what exercise I can and can't do... [I'm] worried about what to do'. One respondent noted that it was difficult to find a balance between doing enough and doing too much: 'Am I doing enough? Am I doing the right exercises for my condition? Knowing how far to go before it becomes "too far" is difficult'.

### Patterns of exercise behaviour

Fifty-two percent of respondents (95/183) reported that they currently undertook regular exercise at the intensity of a brisk walk or above. This was significantly less than the proportion who reported regularly exercising prior to the diagnosis of PH (61%,  $n = 112/184$ ;  $\chi^2(1) = 7.6$ ,  $p = 0.006$ ). Among those who exercised, the amount and types of exercise performed before and after PH diagnosis were similar, with walking the most common form of exercise (see Table 2).

### Exercise knowledge and experiences

Seventy-seven percent of participants (143/186) reported that they had been advised about exercise benefits, while approximately half had received exercise guidelines

**Table 3.** Exercise attitudes and experiences among people living with PH.

	Total <i>n</i>	Yes <i>n</i> (%)	No <i>n</i> (%)
Received information/advice regarding benefits of exercise for PH	186	143 (77)	43 (23)
Received exercise guidelines for PH	183	103 (56)	80 (44)
Received advice regarding symptom monitoring and safety during exercise	182	106 (58)	76 (42)
Personally experienced problems (adverse events) while exercising	180	113 (63)	67 (37)
Expressed concerns regarding exercise	177	85 (48)	92 (52)
Expressed anxiety related to exercise	177	66 (37)	111 (63)
Expressed family or carer concerns related to exercise*	177	45 (25)	74 (42)
			*'Don't know' 58 (33)

(103/183, 56%) and/or been educated about PH-specific precautions and symptoms to be aware of during exercise (106/182, 58%) (see Table 3). More than half the cohort (113/180, 63%) reported a previous adverse event during exercise (discussed below). Many reported exercise-related concerns (85/177, 48%) and/or anxiety about exercise (66/177, 37%). Participants who experienced a prior exercise-related adverse event were significantly more likely to report exercise-related concerns ( $\chi^2(1) = 11.9, p = 0.001$ , odds ratio 3.1, 95% confidence interval 1.6–5.9) and/or anxiety ( $\chi^2(1) = 6.6, p = 0.01$ , odds ratio 2.4, 95% CI 1.2–4.7).

### Difficulties with exercise

Shortness of breath (22% coverage in NVivo thematic analysis) and fatigue (9% coverage) were the most commonly noted exercise-related negative experiences. Respondents noted 'any physical activity makes me feel breathless and ghastly', 'I experience breathlessness on even mild exertion... I can barely put one foot in front of the other'. Respondents also reported that exercise precipitated other cardiac symptoms (10% coverage), such as 'dizziness, chest pain' and hypotension; 'If I take it too far I get a very irregular heart beat'; 'if it is a bad PH day, I get dizzy with very little exertion'.

Exercising outside a supervised context raised safety concerns for respondents: 'I'm fearful that I will get short of breath and pass out. Or, that I will walk somewhere and then not have the energy to get back home'. Other anxieties raised included feeling 'isolated [regarding] exercise', and feeling 'self conscious about exercising in front of other people'.

### Barriers to exercise

When asked to identify barriers to exercise (via selection from a multiple-choice list and/or the opportunity to provide free-text answers), participants most commonly identified: (i) fatigue (135/738 total responses, 18%); (ii) dyspnoea (124/738, 17%); (iii) frustration at physical limitations (65/738, 9%); and (iv) pain (64/738, 9%) as the most

**Table 4.** Perceived barriers to exercise.

Barrier	Frequency of response <i>n</i> (%)
Too tired or fatigued	135 (18)
Too breathless	124 (17)
Frustration at physical limitations	65 (9)
Limited by pain	64 (9)
Fear	53 (7)
Cost	46 (6)
Safety concerns	43 (6)
Exercise is unenjoyable	39 (5)
Limited mobility	37 (5)
Unsure what exercise to do	35 (5)
Lack of time	29 (4)
Previous adverse event while exercising	23 (3)
Unable to travel/access exercise facilities	20 (3)
Advised not to exercise by doctor	12 (2)
Advised not to exercise by family	3 (0.4)
Other (e.g. medical co-morbidities, lack of company, weather)	10 (1)
<b>Total number of responses</b>	<b><i>n</i> = 738</b>
<i>(provided by n = 175 respondents)</i>	

Data were derived from a question asking respondents to identify all perceived barriers to exercise. Each respondent could select multiple options; therefore, the total number of responses is larger than the number of individual respondents.

common exercise barriers (Table 4). Fear, safety concerns and cost were also commonly cited as barriers (Table 4).

Motivation to exercise was noted to be difficult (9% coverage): 'Even normal people need motivation to exercise - for PH patients, the thought of walking a few hundred metres is daunting... We tend to feel tired and afraid of getting more breathless'. Embarrassment and self-consciousness when exercising in public were repeatedly noted to impact motivation: 'it is intimidating to have "normal" people around you, exercising at their normal capacity while

**Table 5.** Perceived enablers of exercise.

Enabler	Frequency of response n (%)
Having access to appropriately qualified staff to guide and supervise exercise	92 (16)
Knowing that exercise will help/improve symptoms of PH	91 (16)
Having a structured exercise programme to follow	89 (15)
Having access to a PH-specific exercise group	84 (14)
Personal benefits and positive feelings gained with exercise (good feelings)	75 (13)
Regular monitoring and assessment of progress	72 (12)
Social support from family and friends	45 (8)
Regular reminders to exercise (e.g. messages, prompts)	24 (4)
Other	15 (3)
<b>Total number of responses</b> (provided by n = 169 respondents)	<b>n = 587</b>

Data were derived from a question asking respondents to identify all perceived enablers of exercise. Each respondent could select multiple options; therefore, the total number of responses is larger than the number of individual respondents.

you're very much slower'. Respondents also noted that initiation could be problematic 'It is often hard to get going on a bad day'; and that immediate physical benefits of exercising were often not felt 'One misses the physical reward afterwards that never comes, [exercise] only makes you exhausted'.

While most perceived barriers to exercise were intrinsic to participants, extrinsic factors such as cost and lack of service accessibility were noted (4% coverage): 'The ability to find somewhere you can go as a group to exercise with people that have similar capabilities, and to find an instructor that understands your capabilities, is very difficult'. Respondents were concerned that accessible community services did not have the understanding or expertise to provide adequate supervision and guidance for people with PH: 'Local gyms are set up for weight loss or strength training, not my condition'. Certain environmental conditions were also noted to make exercise more difficult, including 'inclines' and 'humid weather conditions'.

### Enablers of exercise

When asked to identify enablers of exercise for people with PH, the most common response was access to appropriately qualified staff to supervise exercise (16%, 92/587), followed by knowing that exercise would improve symptoms of PH (16%, 91/587); and having a structured exercise programme (15%, 89/587) (Table 5).

Education about the importance and benefits of exercise for PH was noted as a prominent priority and facilitator

(7% thematic coverage): 'It would be beneficial to have someone explain how exercise can assist with the symptoms of PH as well as introduce [how to exercise] to patients'. Respondents expressed a desire for education on how to recognise and manage symptoms while exercising: 'Knowing my limitations would be great - to know how to exercise without damage (would be) great'.

Respondents also noted the need for greater public awareness and education to combat a widespread lack of understanding about PH: 'People know and understand asthma, and cancer. But I've had this for almost 12yrs and still my GP does not understand my condition - friends and family think it's just asthma'.

Respondents expressed different preferences for exercise settings. Some noted the flexibility of home-based exercises: 'since I received a recumbent stepper at home, I exercise much more frequently because it doesn't entail me getting dressed, getting in my car, and trying to make it somewhere...'. Others noted a preference for accessing formal supervised, group exercise: 'A group setting really helps. To be with people who are going through the same thing and who understand'. However, travel and distance were noted to be important considerations for some participants: 'City areas have several programmes they can access, but in rural areas it's harder to find...Travel distances and no public transport prove a problem'.

### Access to multi-disciplinary rehabilitation services for PH

Respondents were asked questions to assess their ability to and desire to access a multi-disciplinary rehabilitation service for PH. While almost all respondents (159/172) reported that access to this type of service would be helpful, only 24% (41/169) stated that such a service was accessible where they lived. There was no difference between the proportion of respondents living in urban versus rural areas who reported having access to such a service ( $p = 0.97$ ).

Participants were asked to rate the perceived importance of five different components of rehabilitation for people living with PH (Table 6). Overall, there was a significant difference in importance ratings between the five features ( $\chi^2(4) = 82.4$ ,  $p < 0.001$ ). Post hoc comparisons revealed that education about exercise and PH was perceived as more important than all other features ( $p < 0.001$  for all four comparisons). This was followed by access to supervised exercise sessions with a physiotherapist ( $p = 0.004$ ) and psychology services ( $p = 0.013$ ). Medical supervision of the rehabilitation programme and access to occupational therapy were perceived to be the least important features (see Table 6).

Respondents noted mixed experiences of existing rehabilitation services within free-text responses. One reported a beneficial experience: 'Pulmonary rehabilitation classes are an essential part of treating PH. They have helped me tremendously and encouraged me to exercise on a daily basis'. However, others noted difficulty accessing

**Table 6.** Perceived importance of different features of a multi-disciplinary rehabilitation service for pulmonary hypertension.

	Total <sup>a</sup> n	Essential n (%)	Very important n (%)	May be useful n (%)	Of little importance n (%)	Unimportant n (%)
Education about the condition PH	171	83 (49)	67 (39)	16 (9)	3 (2)	2 (1)
Access to supervised exercise sessions with a physical therapist	173	68 (39)	64 (37)	35 (20)	5 (3)	1 (1)
Psychology intervention and support	173	52 (30)	61 (35)	48 (28)	8 (5)	4 (2)
Occupational therapy (for promoting independence in daily activities)	167	42 (25)	55 (33)	48 (29)	17 (10)	5 (3)
Having a doctor oversee the rehabilitation programme	170	38 (22)	56 (33)	61 (36)	10 (6)	5 (3)

<sup>a</sup>The total number of responses for each service feature.

rehabilitation, or disappointment with the content and perceived level of expertise: 'I took pulmonary rehab for a bit at a local hospital, but they were woefully undereducated on PH; I knew more than they did, and so their supervision did not feel at all safe to me'. Lack of recognition of rarer conditions, such as PH, appeared to be problematic: 'I went to a pulmonary rehabilitation programme, but it wasn't for me; it was all about COPD and nobody understood'.

## Discussion

To our knowledge, this is the first international study to examine patterns of behaviour, attitudes and the subjective experience of exercise for people living with PH. It extends on previous work<sup>14,15</sup> to further understand the experience of living with PH, here with a particular focus on engaging in physical activity and rehabilitation. This study identified considerable uncertainty regarding the importance and safety of exercise among people with PH, together with reduced levels of physical activity post-diagnosis and fear and anxiety. Numerous barriers to exercise were identified; largely internal factors including breathlessness, fatigue and psychosocial barriers such as embarrassment, fear and isolation. Respondents strongly desired access to a multi-disciplinary rehabilitation service tailored for PH, although the availability of such services appeared limited. Access to PH-specific education, supervised exercise programmes and psychology support were felt to be important components of a multi-disciplinary service that would help facilitate exercise in this population.

While respondents noted the importance of exercise for the general population, many expressed uncertainty regarding exercise in the setting of PH, where it was perceived to be less important. The proportion of people with PH engaging in regular physical activity was lower than pre-diagnosis, in keeping with previous literature.<sup>6,7,9</sup> This may result from exercise barriers, together with uncertainty regarding the role and safety of exercise. More than half the study cohort (63%) reported a previous adverse event during

exercise. This was associated with a greater likelihood of exercise-related concerns and anxiety and suggests that eliciting a detailed exercise history and addressing such concerns is an important consideration.

The present study identified internal and external barriers to exercise in PH. External barriers included cost and limited access to staff experienced in managing patients with PH. However, intrinsic, patient-related barriers were dominant and identified more commonly by respondents. These included symptoms such as breathlessness and severe fatigue; as well as physical co-morbidities such as pain that impacted physical function. Psychosocial barriers such as embarrassment, social isolation and fear of adverse events were prominent. Respondents described difficulties with motivation, such as lacking energy to initiate exercise while feeling unwell, exercising despite little perceived gain and/or feeling worse with exercise. These findings are congruent with those of a recent study of patients with PAH and/or CTEPH, where internal factors including poor self-discipline, lack of energy and low self-interest were the most frequently reported barriers to physical activity.<sup>14</sup>

Our recent study of physicians involved in the management of PH identified similar perceived intrinsic barriers to exercise for patients with PH.<sup>16</sup> While physicians noted patient ill-health, low motivation and lack of understanding as major exercise barriers, they did not identify other psychosocial barriers noted by their patients such as fear, embarrassment and social isolation. This highlights the importance of considering multiple consumer perspectives to inform clinical management and co-design of clinical services.<sup>17</sup>

Education about the safety, benefits and characteristics of exercise specific to PH emerged as an important enabler. Behavioural change techniques such as motivational interviewing, providing structured information on when and where to exercise, setting graded tasks and self-monitoring (for example with heart rate or fitness activity monitors) may help to improve patient self-efficacy and be beneficial for engagement.<sup>18</sup> Patients should be guided to physical

activities they enjoy, as exercise enjoyment and competence may enhance adherence.<sup>19</sup>

Perceived enablers of exercise were largely external. Most respondents favoured having access to a structured PH-specific exercise programme, supervised by a qualified healthcare professional. Supervised, face-to-face exercise sessions (conducted in either the inpatient or outpatient setting) have been shown to improve exercise capacity and quality of life for people with PH.<sup>5,20</sup> Recent guidelines to promote utilisation of outpatient cardiac rehabilitation noted that patients should be given a choice regarding the format that best suits them (face to face or home based).<sup>21</sup> However, access to centre based rehabilitation may be limited, while home-based models may not always be appropriate; thus individual choice of a variety of settings would likely be most useful.

Some respondents in the present study noted the ability to perform home-based exercises as an enabler, due to convenience. This has also been noted in the literature, with greater adherence when cardiac rehabilitation is able to be done (at least partially) in a home-based setting.<sup>21</sup> While home-based rehabilitation models may be convenient and overcome access barriers, it is important to note that the current evidence-base for such services for PH remains limited. To date, a limited number of small studies<sup>22–24</sup> have examined the safety and efficacy of home-based exercise interventions for PH. The most recent study by Babu et al.<sup>24</sup> of 84 patients with all forms of PH suggested that a home-based walking and exercise programme had beneficial effects on walking distance, quality of life and WHO functional class; though further research is needed.

Home-based exercise programmes should only be implemented after patients have been assessed and deemed safe to exercise at home.<sup>25</sup> The use of monitored tele-health service models, where physiotherapist intervention, supervision and education can be delivered remotely, may also be beneficial, and warrant further investigation.

Education about exercise and PH for those with the condition, and among health care professionals and the wider general public, was emphasised by respondents as an important enabler. This aligns with previous work,<sup>26</sup> where an education manual improved awareness of the benefits of exercise among people with PH. Many of our respondents expressed uncertainty regarding appropriate exercise practices for PH. This may reflect uncertainty among PH physicians<sup>16</sup> and physiotherapists<sup>27</sup> themselves regarding optimal exercise prescriptions for PH and may be compounded by a lack of clear exercise guidelines to guide treating clinicians.<sup>5</sup> Participants noted that their routine healthcare providers required further education and expertise to safely understand and manage patients with PH. Thus, it appears that both patients and healthcare providers would benefit from further education to improve confidence and overcome uncertainty.

Almost all respondents (92%) desired access to a multi-disciplinary rehabilitation service for PH. However, <25%

of respondents reported having access to this, with no significant difference observed between urban and rural areas. This was somewhat surprising and suggests that other factors beyond geographical location may limit service accessibility for urban and rural patients alike. Common factors may include limited PH awareness among healthcare professionals and therefore low rates of referral to existing services; and limited availability of qualified health staff with the skills and knowledge to manage PH patients.

The components of a multi-disciplinary rehabilitation service that respondents rated as most important were patient education, supervised exercise and psychology intervention. Although most participants had previously been advised on exercise benefits (143/186, 77%) and half had been advised on exercise frequency (103/183, 56%), and symptoms to be mindful of (106/182, 58%), education was still rated as the most important component of a multi-disciplinary rehabilitation service; indicating a strong desire among patients to be informed and empowered to take an active role in their health management.

Almost all rehabilitation programmes studied for PH populations to date have included a structured exercise programme supervised by physiotherapists.<sup>5</sup> In contrast, other components of multi-disciplinary rehabilitation have not been well evaluated.<sup>5</sup> Given the present findings, we would advocate for the inclusion of psycho-educational services in PH rehabilitation programmes. Anxiety and depression are common in patients with PH, with a prevalence of 7.5–53% for depression and 19–51% for anxiety.<sup>28</sup> Further, exercise-related anxiety was reported by many participants in this study. Psychotherapy, psychotropic medications and/or progressive muscle relaxation techniques may be useful in this context.<sup>29</sup>

### Study limitations

The generalisability of study results may be limited by the voluntary nature of the survey and self-selection of participants. Participants were likely to represent a highly engaged subset of the PH population. While the survey was offered in multiple formats (paper and electronic), the use of online survey advertising and dissemination may have favoured those with internet access, often a more literate population,<sup>30</sup> and those actively engaged with PH groups. Indeed, 67% of the present cohort reported an affiliation with at least one consumer support group, and levels of education in the present cohort appeared higher than the Australia population average.<sup>31</sup> Therefore, our results may have been derived from a particularly health literate and educated PH patient population; thus, uncertainty and education needs in the population at large may be even more pronounced. Further, survey responses were derived from a predominantly female population. While the incidence of PH is higher in women than men,<sup>32</sup> the magnitude of this difference appears compounded in this study (likely due to



responder bias), and therefore experiences and perspective unique to men may be under-represented.

The paper version had a response rate of 39%. Given the nature of online study recruitment, it was impossible to determine the size of the total source population who were notified about the survey, and the proportion of those who responded. Hence, generalisability may be limited. The survey was only available in English. While participants were included from 19 different countries, there was not sufficient power within the current sample distribution to perform subgroup analyses based on geographical location, or PH subtype. Cultural factors may impact attitudes and exercise behaviour and may differ across geographic regions and countries, therefore generalisability may be limited.

We did not collect detailed data on clinical PH variables that may have affected patients' experience of exercise (for example, WHO functional class or PAH specific medications), as we felt there was considerable potential for recall error and no means of verifying the accuracy of those data. Further, as >50% of the cohort was more than eight years post-diagnosis, recall bias may have influenced responses, particularly regarding pre-diagnosis behaviour.

## Conclusion

People with PH were aware of the benefits of exercise for the general population but expressed uncertainty about the importance of exercise for them. Respondents reported less physical activity after a diagnosis of PH and identified multiple barriers to exercise, often associated with anxiety and previous exercise-related adverse events. Exercise barriers included intrinsic factors such as breathlessness, fatigue and psychological distress; with external barriers such as cost and service accessibility also noted. The availability of PH-specific multi-disciplinary rehabilitation services appeared limited but was highly desired by consumers. Consumers emphasised the importance of such services providing education about PH, as well as supervised exercise programmes and psychological support. Alternative service models such as tele-health and supported home-based exercise programmes may complement currently available PH services.

## Acknowledgements

The authors gratefully acknowledge Annette Whitaker, CEO and Founder, Pulmonary Hypertension Association Australia (PHAA), and Joan Godber, President (PHAA), Kevin Burke (Vice President) and PHAA members for support. Thank you to the PH patient support groups who shared this survey with members and to all respondents who shared their experiences.

## Contributorship

Study conception and design: K.S.W.C. and C.T.S. Funding acquisition: K.S.W.C., K.B. and C.T.S. Project administration: K.S.W.C., K.B. and C.T.S. Data acquisition/survey dissemination: K.S.W.C., K.B., C.T.S., E.K. and P.K.K.W. Data

analyses: K.S.W.C. and C.T.S. Interpretation of results: K.S.W.C. and C.T.S. Drafting of manuscript: K.S.W.C. Review, revision and approval of final manuscript: all authors.

## Conflict of interest

The author(s) declare that there is no conflict of interest.

## Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: K.S.W.C. was supported by the RACP Research Entry Scholarship. This work was supported by the St Vincent's Clinic Foundation Multidisciplinary Grant.

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