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How is the education component of pulmonary rehabilitation delivered in practice—Is it patient-centred?

Nicola J. Roberts | Lisa Kidd | Kim Kirkwood | Jane Cross | Martyn R. Partridge

INTRODUCTION

Pulmonary rehabilitation (PR) is a crucial part of the management of respiratory disease, mostly delivered to those with COPD although this has widened in recent years to encompass bronchiectasis, interstitial lung disease (ILD) and asthma. PR 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 to health-enhancing behaviours’. Theoretically, PR should equip participants with the right tools to take control of their condition, which should include the acquisition and use of self-management skills.
skills as well as motivating and empowering participants. Specific skills are needed by PR staff to deliver this, including training in motivational interviewing and shared decision-making. Key components of self-management education include smoking cessation, self-recognition and treatment of exacerbations, nutritional advice and management of dyspnoea. Follow-up support, for example maintenance exercise programmes, should be an integral part of PR. It is important that the education component of PR does not just facilitate knowledge transfer but promotes sustained behaviour change. PR can involve delivery which is often didactic, rather than person-centred, where the educator is the expert delivering information to a potentially passive patient. Other specialities have shown the positive impact of delivering education which is more person-centred (ie Small group and interactive). Participants should be involved in goal-setting, decision-making and tailoring education and interventions to their needs and priorities.

Published research has identified that there is significant variation in the content and delivery of education within PR programmes. The most recent British guidance on PR does not specify the core components of education in PR and how this should or could be delivered in practice. This survey study set out to identify in more detail what educational content is delivered in practice and how is it delivered within PR across Scotland.

2 | MATERIALS AND METHODS

2.1 | Sample

The Scottish Pulmonary Rehabilitation Action Group (SPRAG) is a multidisciplinary, national group which aims to raise the profile and quality of PR services across Scotland. Where possible, SPRAG has regional leads working in PR in each of the NHS Board areas. Of the 14 NHS Boards, 11 have a PR service and a SPRAG representative regional lead. All of the regional leads were physiotherapists.

2.2 | Data collection

Questionnaires were sent electronically to the 11 regional leads via the Scottish Pulmonary Rehabilitation Action Group (SPRAG) with a supporting email to explain the purpose of the study. The questionnaires were delivered in January 2018 with 2 months given for completion. A reminder was sent 4 weeks after the initial mailing. Completion of the survey was taken as implied consent.

2.3 | Survey tool

A review of the current published literature about education in PR was used to inform the development of the survey tool providing a total of 40 educational topics. The tool was estimated to take about 30–45 min to complete and consisted of 23 pages covering:

1. **Demographic data**—Data were collected on the PR programme (ie timing/length of educational sessions), team staff mix, usual participants, variations in delivery, referral criteria for PR and outcome measures (especially for education)

2. **Current content and delivery of education within the PR programme**—A list of 40 educational topics was developed from the literature, participants completed details on the time allocation, mode of delivery, staff lead and any educational tools used.

3. **Prioritisation exercise**—Participants were asked to rank which educational topics should be included, and whether they should be addressed within a group or one-to-one session. Details of which type of staff should be involved in the delivery of the topic/session were also collated.

The questionnaire mainly consisted of closed questions using forced choice answers of yes/no or a list from which to select a response. Some questions provided free text boxes to extra information about how services were delivered, details about self-referral, top-up classes, differences in programme delivery and details on how programmes were tailored.

Face validity of the questionnaire was determined by local PR teams and the SPRAG committee. Following discussion, the tool was amended to reflect this feedback and minor adjustments were made. If necessary, individuals were contacted to clarify responses or to provide additional information.

2.4 | Data management and analysis

Data were entered into SPSS for analysis (IBM, Version 24.0) removing any identifiable data at the point of data entry, regional board areas were coded and numbered. Free text data were analysed separately using content analysis. A basic descriptive analysis was produced to provide a narrative of the variation across Scotland.

3 | RESULTS

Responses were received from 9 out of the 11 (response rate 81.8%) Scottish Pulmonary Rehabilitation Action Group
ROBERTS ET AL

(SPRAG) regional leads within Scotland. The responses included 17 PR teams, with a median of 1 team in each region (range 1–3). Regional leads were not in place for 3 of the 14 regions at the time of the survey and thus, our findings reflect practice for 64% (9/14) of PR services delivered across Scotland.

Table 1 shows the delivery and set-up of the PR programmes. There were differences in delivery (use of rolling/block programmes and modes ie tele-based). However, education was predominately community or hospital-based, group-based and face-to-face (ie in person) in all health board areas (100%, 9/9). Eight out of the nine respondents (88.9%, 8/9) reported that those with other conditions still attended the education classes, 55.6% (5/9) respondents reported that the education was adapted occasionally or ran for separate disease groups. Exercise sessions were longer (mean 55 min, range 45–60) compared to education sessions (mean 35 min, range 30–60).

Pulmonary rehabilitation programmes lasted around 7 weeks (range 6–8 weeks) with a typical education programme of 6 (±1.5) h. Education and exercise were usually delivered within the same session, and in most programmes, education was delivered after exercise (88.9%, 8/9). All reported that education session attendances were recorded (100%, 9/9). The minimum number of educational sessions needed for completion of PR ranged from 0 to 12 (mean 6.3), meaning in some programmes participants could be a ‘completer’ in the programme without having to attend any education sessions. Just under half of respondents (44.4%, 4/9) reported the use of top-up classes for appropriate participants, these are usually one-to-one sessions focusing on areas such as inhaler technique and anxiety management.

All respondents (100%, 9/9) reported that sessions were included on enhancing participant’s self-management skills by providing education about their condition, and increasing their confidence. These included medication knowledge, awareness of symptom triggers and controlling symptoms, management of exacerbations and management for emergencies. A third (33.3% 3/9) of respondents reported that literacy assessment or educational level attainment (used as a proxy for health literacy) was undertaken at recruitment to PR programmes within their regions. However, this appeared to be primarily done informally without any structured assessment tools. All asked patients if they needed assistance and understood the questionnaires or observed whether they could complete the paperwork to assess their capability. Two thirds of respondents reported that they developed/implemented a COPD plan with 44.4% (4/9) tailoring this for perceived literacy levels (eg review of reading materials by patient information service/expert group, use of pictorial representation).

### Table 1 Description of PR programmes

<table>
<thead>
<tr>
<th>PR programme characteristics</th>
<th>Frequency %, (number)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Available formats</strong></td>
<td></td>
</tr>
<tr>
<td>In-patient</td>
<td>11.1% (1/9)</td>
</tr>
<tr>
<td>Hospital-based</td>
<td>77.7% (7/9)</td>
</tr>
<tr>
<td>Community-based</td>
<td>88.8% (8/9)</td>
</tr>
<tr>
<td>Tele/internet/video-delivery</td>
<td>44.4% (4/9)</td>
</tr>
<tr>
<td>Home-based</td>
<td>44.4% (4/9)</td>
</tr>
<tr>
<td>Early Post-Discharge</td>
<td>44.4% (4/9)</td>
</tr>
<tr>
<td>Individualised One-to-one</td>
<td>88.8% (8/9)</td>
</tr>
<tr>
<td>Rolling programme</td>
<td>33.3% (3/9)</td>
</tr>
<tr>
<td>Mixed at different sites</td>
<td>11.1% (1/9)</td>
</tr>
<tr>
<td><strong>Education class size mean, (SD)</strong></td>
<td>12.1 (5.3)</td>
</tr>
<tr>
<td><strong>Number of attendances per week mean, (SD)</strong></td>
<td>1.7 (0.4)</td>
</tr>
<tr>
<td><strong>Exercise session length (min) mean (SD)</strong></td>
<td>55.0 (7.5)</td>
</tr>
<tr>
<td><strong>Education session length (min) mean (SD)</strong></td>
<td>35.0 (10.6)</td>
</tr>
<tr>
<td><strong>Programme length (weeks) mean (SD)</strong></td>
<td>6.6 (0.9)</td>
</tr>
<tr>
<td><strong>Total education session hours mean (SD)</strong></td>
<td>6.4 (1.5)</td>
</tr>
<tr>
<td><strong>Education delivered before or after the exercise component</strong></td>
<td></td>
</tr>
<tr>
<td>Before</td>
<td>11.0% (1/9)</td>
</tr>
<tr>
<td>After</td>
<td>88.8% (8/9)</td>
</tr>
<tr>
<td><strong>No of education sessions per programme mean (SD)</strong></td>
<td>10.3 (2.6)</td>
</tr>
<tr>
<td><strong>Number of educational sessions needed for completion mean (SD)</strong></td>
<td>6.3 (4.4)</td>
</tr>
<tr>
<td><strong>Follow-on care provided after completion (education and/or exercise)</strong></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>44.4% (4/9)</td>
</tr>
<tr>
<td>Yes</td>
<td>44.4% (4/9)</td>
</tr>
<tr>
<td>If needed</td>
<td>11.1% (1/9)</td>
</tr>
<tr>
<td>After care—support group available</td>
<td>44.4% (4/9)</td>
</tr>
<tr>
<td>After care—telephone support available</td>
<td>44.4% (4/9)</td>
</tr>
<tr>
<td>After care—supervised exercise</td>
<td>66.6% (6/9)</td>
</tr>
<tr>
<td><strong>Social activities before/after the rehabilitation sessions (ie tea/coffee/catch-up)</strong></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>55.5% (5/9)</td>
</tr>
<tr>
<td>Tea/coffee</td>
<td>44.4% (4/9)</td>
</tr>
<tr>
<td><strong>Does the service access self-referrals?</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.0% (0/9)</td>
</tr>
<tr>
<td>No</td>
<td>100.0% (9/9)</td>
</tr>
<tr>
<td><strong>Can participants self-refer back to PR</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>11.1% (1/9)</td>
</tr>
<tr>
<td>No</td>
<td>88.8% (8/9)</td>
</tr>
</tbody>
</table>

Are patients with the following conditions accepted

- Pulmonary fibrosis | 100.0% (9/9)
- Cystic fibrosis | 55.5% (5/9)

(Continues)
Staff delivering PR education

Figure 1 shows the PR team structure. The survey asked about the PR team members, who were involved in teaching within PR, and although many were experienced, with a wide range of experience (COPD diploma, PR courses, MSc and other accredited courses) none had specific teaching qualifications (eg PgCert) (Figure 2).

Educational topics delivered as part of PR

Participants reported that most of the educational topics listed were delivered (Supporting tables). Less frequently included topics were: use of oxygen (66.7%, 6/9), information about benefits/welfare rights (66.6%, 6/9) and how to make end of life decisions (55%, 5/9). Advance directives (33.3%, 3/9), sexuality (33.3%, 3/9) and ‘communicating with your healthcare provider’ (33.3%, 3/9) were infrequently included in PR. Most sessions were delivered in a group format with one-to-one sessions less likely. In some cases, a mixture of both group and one-to-one were used, that is chest clearance (44.4%, 4/9), anxiety management (44.4%, 4/9), smoking cessation (33.3%, 3/9) and improving self-efficacy and confidence (33.3%, 3/9).

Very few educational sessions (<2) appeared to last longer than 45 min. Some were found to last between 30 and 45 min (44.4%, 4/9), for example, pharmacology (44.4%, 4/9) the benefits of exercise (44.4%, 4/9) and chest clearance (44.4%, 4/9). Most topics were delivered in shorter sessions, lasting 15 min or less (pathophysiology 33.3%, 3/9; medical tests 55.6%, 5/9; oxygen and NIV 33.3%, 3/9). The topics which are not routinely covered or only covered when requested are shown in the Supporting tables.

Who delivered the education and what tools were used?

Most participants reported specialist physiotherapists were often the lead for sessions such as the benefits of exercise (88.8%, 8/9), anxiety control (55.6%, 5/9), breathing exercises (88.8%, 8/9) and strengthening exercises (88.8%, 8/9). Specialist nurses predominately led on sessions involving use of inhalers (55.6%, 5/9), smoking cessation (44.4%, 4/9), recognising exacerbations (66.7%, 6/9), action plans (44.4%, 4/9) and oxygen (44.4%, 4/9). Several educational sessions did not have a lead identified including end of life, advance directives, benefits and travel and leisure activities.

Interactive lecturing, where opportunities were made to involve PR participants in topic discussion, were the most commonly used style for most sessions with more than half of respondents (55.6%, 5/9) reporting this was used in 33
of the 40 sessions. Demonstration techniques were used in some sessions with more than half of the respondents (55.6%, 5/9) using this technique in eight sessions (eg use of inhalers, breathing strategies, chest clearance, breathing and strengthening exercises). Motivational interviewing or case studies were used infrequently with three or less respondents using this technique in 34/40 sessions, and four or less using case scenarios in 20/40 sessions. There was very little use of peer observation, apart from the session on support groups. Group discussions were well utilised, with more than half of participants using these in 24 out of the 40 sessions. Around half used Powerpoint (3–4/9) for a few sessions but there was evidence of greater use of printed materials for many topics. (Supporting tables).

Examining how individual sessions are planned and organised has shown that only in one session (energy conservation/pacing) did more than half the respondents undertake an assessment of information needs. The participants were asked if they evaluated PR participant’s self-efficacy for any of the educational sessions which could have included the use of formal tools or informal assessment. However, this only occurred for one session, inhaler technique, where just over half of the respondents reported assessing self-efficacy (44.4%, 4/9). There was no use of learning contracts in any sessions apart from the session on anticipatory care planning (33.3%, 3/9). Some respondents reported previously that all of their materials were assessed, but for individual sessions there was no report of adapting the materials for literacy levels at the point of delivery.

### 3.4 | Outcome measures

A range of outcome measures were reported from respondents around assessment of attendees’ satisfaction and self-management skills based on the education that they received within the programmes. The tools reported included the Consultation and Relational Empathy (CARE) questionnaire, Patient Activation Measure (PAM), Chronic Respiratory Questionnaire (CRQ), Lung Information Needs Questionnaire (LINQ) and COPD Assessment Test (CAT).17–21

## 4 | DISCUSSION

This survey is part of a programme of work examining how education is delivered in PR. Our previous systematic review showed that in the published literature several topics were not featured and there were few tools used to evaluate the effectiveness of education.22

This cross-sectional survey provides data on 64% of the PR sites across Scotland (response rate of 81.8%, 9/11 respondents), includes data from 17 PR teams across Scotland. This survey set out to examine what is delivered in practice, it is the first to show in detail what educational content is delivered and who is involved in the teams and delivery of education within PR across Scotland.

How we deliver education is important, it is key to pitch information at the right level and give learners a range of tools to help them understand and benefit from the information being delivered. Several studies have shown that around 15% of the population have literacy issues so it is important to ensure that materials are appropriate and accessible for all participants.23–25 We already know that in a COPD population there will be high levels of poor health literacy, impacted in part by the increase in dementia and cognitive decline in older adults.26 In our study we found a small number of respondents reported informally undertaking a literacy assessment, taking cues from participants, but teams did not use formal assessments or questionnaires.
In some areas help was offered to complete questionnaires and other written materials, such as exercise diaries, but this was not reported in all health areas, despite published evidence which suggests that healthcare professionals may often overestimate literacy levels. 27,28 Levasseur et al suggest that most of those working in a rehabilitation environment do not know enough about health literacy and it is not embedded into their practice.29 This suggests staff need to receive training to be able to recognise those with literacy issues and improve the delivery of education as this problem will increase as the population continues to get older. There was frequent use of Powerpoint and printed materials in this study which was also highlighted in the National COPD audit programme.30 Part of the focus of the National COPD Audit focussed on the availability of formats for other languages or Braille formats, however there was no mention of tailoring or checking materials for health literacy levels in the UK National Audit. 30 In contrast, our study has shown a few respondents reported that their reading materials were assessed for reading age and literacy levels. However, it is important to consider not only health literacy but also different learning styles, for example VARK.31 Educational materials should use different formats to ensure that PR participants have a range of ways to learn.

There needs to be a systematic approach to review the learning needs of individuals/groups for literacy or learning difficulties and appropriate tailoring of educational sessions. Often within teams there were no specific leads for some of the more holistic sessions which may impact on whether these sessions are included, delivered regularly or updated. Innovative approaches are needed to deliver PR to ensure that sessions are not just Powerpoint and handouts. Use of expert patients, demonstrations and other tools are needed to enhance delivery and motivate participants to become effective self-managers. The use of expert patients is suggested in the BTS guidance16 and the ATS workshop32 suggests staff may need additional training to deliver education effectively. Motivational interviewing is a well-recognised, effective tool to promote behaviour change,33 but it has been shown as difficult to implement.34 Motivational interviewing or case scenarios were used infrequently. A small number of participants (22.3%, 2/9) reported using motivational interviewing in eight sessions including, goal setting, depression, psychological impacts of the disease and benefits of exercise. However, in the smoking cessation session, 33.3% (3/9) of participants used motivational interviewing techniques.

In the current PR guidelines and publications1-3 the educational topics focus on the biomedical aspects of respiratory disease such as pathophysiology and treatment of exacerbations. There are other important topics such as educating participants to recognise symptoms of exacerbations and supporting patients on how to use inhalers well. Completing of a PR programme should develop individuals to be ‘effective self-managers’ through knowledge acquisition and development of self-management skills. Other components of the programme should also inform participants of the benefits of amenities such as support groups, welfare and benefits available.35 Topics which are less biomedical and more holistic, were not well-covered within the PR programmes, these included topics such as end of life decisions, advanced directives, sexuality and key areas including communicating with your healthcare provider. None of the respondents suggested removing any of the topics, only that they should last for a shorter period of time.

Those with COPD and other respiratory long-term conditions frequently have high levels of anxiety and depression.36 Our findings showed that just under half of the health areas incorporated tailoring for those with high HADS scores (or similar) for anxiety and or depression including more support and one-to-one sessions. Another way to tailor PR to individual needs is to provide additional resources such as top-up classes, to provide one-off sessions (usually one-to-one) on anxiety management, inhaler technique etc In this survey, these were reported to be available in just under half of the health areas, usually one-off one-to-one sessions covering topics like inhaler technique and anxiety management usually by the team or referral to appropriate services. This type of flexible approach may allow more effective management of the programme to balance access for first-time attendees and repeat attendees.

There is an increasing number of participants who attend PR who do not have COPD but have another condition such as ILD, or who are pre or post-operative for lung cancer. This makes delivery of education more complex and highlights the limitations of a standard education programme and the need for a more tailored approach. Our study has shown that a high number of attendees with other respiratory conditions do attend the education sessions.

Our results have shown that evaluating the effectiveness of education in PR tends to be undertaken using patient feedback sheets or comments. Four respondents reported using generic feedback forms to assess outcomes. Our survey findings revealed no specific educational outcome measure was used to measure knowledge or behaviour change specific to education which is important to be able to assess educational outcomes in a structured manner. ‘Patient learning’ was highlighted in the CHSS PR report37 as an outcome measure but it was only used in 45.5% (5/11) of the health areas, much lower than measurements of exercise capacity and QOL both measured routinely in a much larger number of sites. Thirty-three per cent of PR sites in the National UK wide COPD audit programme measured knowledge gained during education.30 Tools are available to measure acquisition of knowledge (eg LINQ, UCOPD, Bristol Knowledge questionnaire).38-40 The Lung
Information Needs Questionnaire (LINQ) questionnaire\textsuperscript{20} does measure knowledge but was used infrequently (n = 1). There are other tools which could show mastery of skills, self-efficacy and some evidence of self-management skills such as the Patient Activation Measure (PAM) and the PRAISE tool,\textsuperscript{18,41} these could be used to assess the effects/effectiveness of the education component of PR.

Education outcomes are poorly monitored and measured in PR. Appropriate outcome measures need to be implemented to ensure education is delivered in an effective way to empower patients to manage their conditions. Monitoring these outcomes could facilitate greater tailoring of content for individual needs and better training for PR professionals to facilitate the development and efficacy of their educator role.\textsuperscript{29} Appropriate tools need to measure the effectiveness of current programmes to ensure outcomes are being measured. Education needs to be delivered in patient-centred ways, incorporating literacy skills, specific respiratory conditions and timing with a mixture of learning approaches utilising expert patients where possible.

We acknowledge a limitation of this study is that we did not assess patient views on what should be included as content in the educational components of PR programmes, thus further work on this aspect would be valuable to inform future design and delivery of education within PR programmes.

Future work needs to investigate patient’s experiences of educational components of PR and their expectations of the programmes.

CONFLICT OF INTEREST
The authors declare that they have no conflicts of interest with the content of this article.

AUTHOR CONTRIBUTIONS
All authors were involved in the design, analysis and write-up of the study.

DATA AVAILABILITY STATEMENT
Data available on request from the authors due to privacy/ethical restrictions.

ETHICAL APPROVAL
Gatekeeper approval was given by The Scottish Pulmonary Rehabilitation Action Group (SPRAG) to disseminate the survey via the regional leads. Ethical approval for the project was obtained from the School of Health and Life Sciences ethics committee at Glasgow Caledonian University (HLS/NCH/17/013).

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SUPPORTING INFORMATION
Additional Supporting Information may be found online in the Supporting Information section.

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