

## Wider Consultation on Pulmonary Rehabilitation for Chronic Obstructive Pulmonary Disease

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**Abstract:** In this article we examine whether an innovative mixed method approach could highlight the positive and challenging effects of a Pulmonary Rehabilitation Programme (PRP) on the Quality of Life (QOL) of patients with Chronic Obstructive Pulmonary Disease (COPD). In 2012, we conducted three consultation workshops in Mid-West Wales, UK, with COPD patients that participated in a PRP, their significant others (e.g. spouses and partners), and healthcare professionals who delivered the PRP. We found that there was a resounding enthusiasm for the content and impact of the programme, particularly in the areas of: increased patient activity, enhanced patient control and confidence, a greater willingness to self-manage treatment, and an increased sense of group belonging. Seven key themes mattered most to our study participants: the patient, physical health, mental health, the programme, professionals and significant others, knowledge and education, and the future. We used these themes to craft a best-practice outcomes document (template) of the benefits and challenges of the PRP to inform and support future service evaluation and delivery.

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## 1. Introduction

In this study of patients, their significant others and healthcare professionals involved in delivering Pulmonary Rehabilitation Programmes (PRPs), we wanted to determine whether using an innovative mixed methods approach could identify the positive and challenging effects of PRP on the Quality of Life (QOL) of patients with Chronic Obstructive Pulmonary Disease (COPD) in order to inform future service evaluation and delivery. This study concentrated on evaluating the PRP from this perspective and working with patients, significant others and healthcare professionals. It did not look at any of the broader aspects of the programme itself. [1]

In this article we discuss the prevalence of COPD and its availability in the UK before exploring methods of collecting experiential knowledge and meaning in relation to being a part of (as a patient), or supporting (as a healthcare professional or significant other) those participating in a PRP (Section 2). We discuss how data can be captured from groups of participants and describe the use of extended consultation workshops, clearly facilitated, to reveal people's perceptions of the benefits and challenges of PRPs. The sampling and recruitment sections describe both homogeneous and heterogeneous characteristics of the wide-ranging participant cohorts. This then leads on to an assessment of the extended consultation workshop sessions, illustrating: how one session led on to the next, how each session disclosed rich data, and how the combined sessions led to a thematic analysis of data (Section 3). From the group-work and consensus building elements seven themes emerged that defined the thematic outcomes document (template) (Section 4). [2]

## 2. Background

COPD is a global health problem with prevalence rates ranging from 3.7% to 11.0% in Europe, 6.3% in Asia, 6.8% in the USA and 9.9% in the UK (WORLD HEALTH ORGANISATION, 2007). It is currently the fifth leading cause of mortality worldwide and is predicted to rise to third by 2020 (WORLD HEALTH ORGANISATION, 2008). COPD is a multisystem, inflammatory disease, characterised by chronic airflow limitation and usually progressive disability (GLOBAL INITIATIVE FOR CHRONIC OBSTRUCTIVE LUNG DISEASE, 2013). The primary cause of COPD in middle to high income countries is smoking (including passive or second hand smoke). Other risk factors include exposure to fumes, dust and air pollution and frequent lower respiratory infections (NHS CHOICES, 2014; WORLD HEALTH ORGANISATION, 2007). Sufferers of COPD are faced with daily life limitations and experience-reduced: activities, health-related quality of life, life choices and work productivity, with many having to give up work due to COPD (DIBONAVENTURA et al., 2012; FLETCHER et al., 2011). Nine out of ten patients have reported an inability to maintain their lifestyles following the onset of COPD and up to half of patients feel that they are unable to plan for the future (FLETCHER et al., 2011). [3]

Figures suggest around 900,000 people are receiving treatment within the UK for COPD (HEALTHCARE COMMISSION, 2006), but the actual number of sufferers might be as high as three million (STANG, LYDICK, SILBERMAN, KEMPEL & KEATING, 2000). Smoking cessation remains a priority in the treatment and management of COPD. Other current treatment approaches include inhaled pharmacological treatments, which improve dyspnea and QOL, and can reduce exacerbations in certain patients (GLOBAL INITIATIVE FOR CHRONIC OBSTRUCTIVE LUNG DISEASE, 2013) but they do not cure the disease or affect the decline in lung function. For those who remain symptomatic despite optimal treatment, out-patient multidisciplinary PRPs are employed to improve QOL (including emotional well-being, improved exercise capacity, reduced dyspnea, and reduced time in hospital following exacerbations) and are recommended in all current COPD guidelines (ibid.; NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE, 2012). [4]

Despite this, PRP availability in the UK remains patchy (BRITISH THORACIC SOCIETY, 2012). Furthermore, issues arise around PRP attendance, dropout rates and non-adherence to long-term exercise programmes to maintain healthy gains once PRP has finished. This presents a number of unanswered questions regarding their long-term benefits (YOUNG, DEWSE, FERGUSON & KOLBE, 1999). Research exploring QOL benefits following PRP has, up to now, concentrated on quantitative evaluation using questionnaires to measure benefits to QOL, including the SF-36 (BENZO, FLUME, TURNER & TEMPEST, 2000), St. Georges Respiratory Questionnaire (BRATÁS, ESPNES, RANNESTAD & WALSTAD, 2010; LAN et al., 2011) and the Chronic Respiratory Questionnaire (CAMP, APPLETON & REID, 2000). Whilst quantitative measures such as these provide useful outcome measurements, they are limited in elaborating the effect of PRP on patient QOL in the short and long-term. Moreover, whilst some qualitative work has concentrated on the effect of PRP from the patient's perspective on, for example, breathlessness (WILLIAMS, BRUTON, ELLIS-HILL & McPHERSON, 2010), dropout rates (FISHER et al., 2007), and self-management (MONNINKHOF et al., 2004), few studies take into account other viewpoints in addition to the patient's viewpoint. In these cases, the significant other's view or the healthcare professional's opinion might be significant when considered as contrary to, or combined with, the patient's perspective. When considered together, these views can provide additional detail about people's aspirations for the future and can enhance the understanding of long-term needs of the patient (HARRIS, SMITH & VEALE, 2008; HOGG, GRANT, GARROD & FIDDLER, 2012; WILLIAMS et al., 2010). Thus a broader understanding of PRP and its impact on QOL could positively affect PRP design and aid in the evaluation and delivery of future services (CAMP et al., 2000; WILLIAMS et al., 2010). [5]

### **3. Materials and Methods**

#### **3.1 Objectives**

Through the synthesis of inductive and deductive quantitative and qualitative methods, we aimed to identify the 12-month outcomes from a PRP undertaken in one UK District General Hospital. We employed half-day consultation workshops (see below) with patients, their significant others and pulmonary rehabilitation healthcare professionals to examine the health impact of a PRP on the QOL of patients with COPD, including the positive and challenging aspects. In this study, QOL was defined through a patient's physical health, mental health and emotional well-being to cover all aspects of a patient's lifestyle, work and social routines and habits. We aimed to complement current knowledge and understanding of health assessment for these patients, to clarify short and long-term needs and expectations, and to design a specific qualitative outcomes document (template) to highlight the benefits and challenges of the Pulmonary Rehabilitation Programme. This outcomes document could be reproduced as an aid to support PRP healthcare professionals' and managers' considerations of future service delivery and evaluation, including how investment in services could be improved and targeted. This article will focus on the qualitative findings of the study whilst the quantitative findings are published elsewhere (see HUTCHINGS et al., 2014). [6]

We obtained local-regional ethical and Research & Development approvals (Project R&D reference HD/12/004) to carry out the study. [7]

#### **3.2 Setting**

The PRP considered in this article is set in a District General Hospital in Mid-West Wales, UK, and includes 18 sessions of outpatient multidisciplinary input from occupational therapists, physiotherapists, dietetics staff, physicians, specialist respiratory nurses, social workers and a smoking cessation counsellor. The PRP has been established for nine years and its content and timings are identical to the approach that GRIFFITHS et al. (2000) suggested with a strong evidence base for a range of beneficial clinical outcomes. The PRP can be tailored to meet the needs of individual requirements and personalised goals can be defined, in order to optimise a patient's physical and social performance. The PRP is pre-empted by individual consultation and healthcare advice from staff linked to the PRP. [8]

### 3.3 Sample

The sample comprised:

- PRP professionals involved with delivery of the programme (n=8; respiratory nurse, two consultant respiratory physicians, respiratory physiotherapist, respiratory occupational therapist, PRP administrator, dietician and specialist pharmacist).
- COPD patients (n=8) who had participated in a PRP in the last two years, or were currently participating in a PRP. Patients were aged between 54 and 74 years. All patients had participated in the PRP by the time this work commenced for at least two months and for those who had already completed the programme up to thirteen months.
- Significant others (n=4). (See Table 1 for details.)

	<b>Study Group, Consultation Group Allocation</b>	<b>Male, Female</b>	<b>Participant Status</b>	<b>Age</b>	<b>Date of PR Programme</b>	<b>Year of Diagnosis</b>
1	SO	M	Significant other	n/a	n/a	n/a
2	SO	F	Significant other	n/a	n/a	n/a
3	SO	F	Significant other	n/a	n/a	n/a
4	SO	F	Significant other	n/a	n/a	n/a
5	PROF	M	Consultant respiratory physician	n/a	n/a	n/a
6	PROF	M	Consultant respiratory physician	n/a	n/a	n/a
7	PROF	M	Pharmacist	n/a	n/a	n/a
8	PROF	F	Occupational therapist	n/a	n/a	n/a
9	PROF	F	Specialist respiratory nurse	n/a	n/a	n/a
10	PROF	F	Physiotherapist	n/a	n/a	n/a
11	PROF	F	Administrator	n/a	n/a	n/a
12	PROF	F	Dietician	n/a	n/a	n/a
13	PT	M	COPD Patient	73	2005	2005
14	PT	M	COPD Patient	66	2010	2010
15	PT	F	COPD Patient	54	2011	2011

	<b>Study Group, Consultation Group Allocation</b>	<b>Male, Female</b>	<b>Participant Status</b>	<b>Age</b>	<b>Date of PR Programme</b>	<b>Year of Diagnosis</b>
16	PT	M	COPD Patient	62	2011	2011
17	PT	M	COPD Patient	66	2011	2009
18	PT	M	COPD Patient	72	2011	1998
19	PT	F	COPD Patient	69	2012	2005
20	PT	M	COPD Patient	74	2012	2005

Table 1: Demographic details of study participants and consultation workshop allocation [9]

### 3.4 Recruitment

Recruitment was purposive from across Mid-West Wales, UK, in order to obtain a wide range of views and public and professional opinions. The patient and significant other groups were approached from across two PRP cohorts (one just concluded and one on-going), to ensure the current status of PRP was considered. The groups included a mix of genders, ages, ethnicities, social backgrounds and economic statuses. Once each patient cohort was approached, patients were encouraged to volunteer until at least six participants had been signed up to the patient workshop, which is an optimal attendance number (BLOOR, FRANKLAND, THOMAS & ROBSON, 2001). Snowball sampling (DENZIN & LINCOLN, 2005) ensured that significant others also heard about the study directly from patients and that the research team could approach them. Once at least six significant others had been identified, all potential study participants were sent a letter of introduction, information sheet and consent form. Anonymity throughout the research was assured, as was data confidentiality. All patients with COPD who were invited to participate in the research study accepted the invitation. All participants were informed that they could withdraw at any stage without the decision influencing patient healthcare, but the full group remained and participated throughout the study. [10]

### 3.5 Study phases

During the one year study, three half day multi-layered, mixed-method consultation workshops took place. [11]

Consultation workshops are facilitated, extended group interactions involving individual and group-work activities and group discussion. Facilitators provide direction, advice, and help sustain participants' interest (CHAPPLE & MURPHY, 1996), paying close attention to the dynamics and cohesion of the group, as views change or are embellished over time. Consultation workshops are staged events with aspects taken forward from one phase to another and complex tasks following on from one another logically. A group's response is thus cumulative,

leading to deeper clarity as work progresses (CLAXTON, RITCHIE & ZAICHKOWSKY, 1980). [12]

A facilitation team organised workshops, managed data capture, analysis and ensured continuity in reporting. All of the consultation workshops were organised in the same way and lasted approximately four hours. All workshops were organised and run by the same facilitators to ensure consistent working practices. Each workshop was facilitated by a different team member with the other members taking notes, observing group interaction and working the tape-recorder. [13]

The study was designed as a three-phase process and data were collected and assessed according to these phases: [14]

### *Phase 1*

The first phase involved using semi-structured interviews to examine: patient and carer quality of life, short and long-term effects of the PRP on physical health, mental health and emotional wellbeing, physical ability, PRP definitions, relationships with family and health professionals and future improvements to PRP delivery. A semi-structured interview approach was chosen as the most appropriate method for this study as it enabled researchers to elicit information freely and openly from participants, but also to encourage a degree of conformity to a pre-defined questioning schedule. For example, participants could talk about their own individual experiences and health concerns, but were also directed to certain areas of interest such as interaction with members of the family or service providers. [15]

Interviews took place in a group setting, with all participants in each of the three groups (patients, significant others, and professionals) present on each occasion. A separate interview schedule was used for each group to enable the researchers to examine nuances between group views, and for the healthcare professionals' interview, the schedule included questions on: service delivery and patient support, professional need and expectation and the impact of the PRP on professional development (see the [Appendix](#) for the interview schedules). [16]

### *Phase 2*

The second phase involved eliciting storied examples of working within, or being supported by, the PRP, improvements to patient health; and perceived impact of the PRP in the short and long-term. During this phase we undertook a nominal group technique (NGT) activity in which participants were asked "What are the positive/challenging aspects of Pulmonary Rehabilitation Programmes for the treatment and rehabilitation of COPD patients?". We used this technique in order to enable a full and detailed group contribution to the debate, as well as individual ranking and scoring of positive and challenging aspects of the PRP to contribute to the debate. Most methods opt for either individual or group work. NGT enables both to take place during the same exercise, and thus offers broader scope and

capacity for capturing both the individual's and the group's opinion. NGT is a commonly used method within healthcare and medical settings (DELBECQ & VAN DE VEN, 1971). The technique normally involves four main phases: a nominal phase, during which each individual silently considers the issues under deliberation; an item-generation phase, during which each individual discloses the results of their deliberation to the group; a discussion and clarification phase, during which the group assures itself that it has understood the items that have been advanced; and a voting phase, during which the items are evaluated and the issues are decided (e.g. a ranking exercise). NGT promotes individual contributions allowing each individual the opportunity to voice his/her opinions. Factors that would normally inhibit participation are avoided and even more reticent group members are encouraged to participate in all phases (CHAPPLE & MURPHY, 1996). [17]

The groups involved were homogeneous in that they were all either patients, significant others or healthcare professionals working together (the same groups that took part in Phase 1). Many heterogeneous characteristics were noted within each group such as differences in a patient's socioeconomic background, age, education and gender. This added to our interest in the group view, and did not detract from their full participation in all activities. In the healthcare professional group, members covered a range of professional disciplines (including dieticians and exercise specialists), but all those present were jointly involved in delivering the PRP. We have used NGT in other settings in a similar fashion and replicated many of the methods used previously to elicit positive and challenging aspects of the PRP (HUTCHINGS, RAPPORT, WRIGHT & DOEL, 2012, 2013). This led to the identification of key aspects which were subsequently amalgamated and refined into approximately ten positive and ten challenging aspects of the PRP from each workshop. All participants taking part in the immediate study team, during Phase two of the consultation workshops, undertook this work. The work was supported by all team members present, and was led by the quantitative health services researcher and statistician (HH). The choice of ten positive and ten challenging aspects was based on a previous study, where we adapted the NGT method to examine perspectives on patient-centred professional care in the fields of nursing and pharmacy (see for example HUTCHINGS et al., 2012, 2014). *Phases 1 and 2* were recorded with notes taken. [18]

Following consultation workshops, we assimilated the findings from each of the three workshops (JANESICK, 2002) and organised positive and challenging aspects of PRP into a series of over-arching themes and sub-categories. Only those aspects that were clearly duplicated were removed. Again this was supported by previous publications in the field, based on tried and tested methods that the team had developed, honed down and verified as appropriate methods for the elicitation of these types of data, over a period of time (HUTCHINGS, RAPPORT, WRIGHT, DOEL & WAINWRIGHT, 2010; RAPPORT et al., 2011). [19]

Following the generation of seven themes (see Section 4), the consultation workshop participants were sent cards listing the themes and were asked to rank



the themes that the research team had derived as key, in order of importance with "1" representing the theme they regarded as being most important and subsequent ranks signifying the themes in diminishing importance (HUTCHINGS et al., 2012). Cards were returned and subjected to further quantitative analysis resulting in a second ranked list of themes and categories (HUTCHINGS et al., 2014, for more detail). Detailed qualitative content for each theme supported the NGT activity and helped articulate fully the set of positive and challenging aspects that each theme contained. Further group-work took place, whereby all team members who had been present during the consultation workshops met on a number of occasions to conduct detailed discussions of emergent ideas and to compare views of emergent themes. This led to a consensus position on key and incidental themes and their associated categories and helped offer meaning to the data whilst clarifying any anomalies or ambiguities within the data (RYAN & BERNARD, 2000). [20]

### *Phase 3*

*Phase 3* involved participants being sent cards which listed refined positive and challenging aspects and asked people to rank the aspects in order of importance (positive and then challenging). This was perceived to be a separate phase. *Phase 2* needed to be undertaken first and its data analysed before the refined lists could be produced which led to a brief break between analyses. [21]

Following *Phase 3*, median ranks, with interquartile ranges, were calculated from each workshop using SPSS (version 19) in order to identify the most important positive and challenging aspects from each group. [22]

### **3.6 Analysis**

Qualitative data was transcribed, collated and evaluated during five group analysis sessions with workshop facilitators and a qualitative adviser (CC). Individual analyses were also undertaken by the qualitative leads (FR/MD), quantitative lead (HH), and research associate (SW). The qualitative analysis of data derived from *Phase 1*, concentrated on addressing the overall study objectives: perceived health impact of PRP, quality of life issues, and descriptions of short and long-term patient needs and expectations. Positive and challenging aspects of the PRP were analysed using the NGT method described within *Phases 2* and *3*. Qualitative data was analysed thematically, with themes derived in direct association with the main study objectives and interview schedule (RYAN & BERNARD 2002). Group sessions helped reduce the qualitative data into manageable units of text, subsumed within seven key thematic headings. Thematic headings were discussed and interpreted in detail and themes were clarified further through in-depth group-work. Qualitative and quantitative outcomes were compared and discussed together towards the end of analysis, and the qualitative themes, as presented in the results section below, contained elements of personal description of the positive and challenging aspects of PRP, alongside the detailed explanations surrounding their views of: QOL, professional practice, professional involvement, and referred to patient expectation and

experience in the short and long-term. The study group agreed data saturation had been reached when no new themes emerged and no changes resulted during thematic configurations following analyses. [23]

#### 4. Results

The thematic outcomes document (template) (see Section 3.1) revealed seven themes that were agreed upon in their order of importance and in their thematic detail by all participant groups. The seven themes are presented below in the order of their significance (including quotations). The themes are: the patient, physical health, mental health, the programme, professionals and significant others, knowledge, education and the future. This article reports the qualitative nature of the themes' content, whilst the NGW activity and outputs are presented elsewhere (HUTCHINGS et al., 2014). [24]

*The patient:* All workshop groups strongly supported the proposition that PRP creates positive changes to patients' health and well-being, leading to gains in patient confidence, increased self-commitment and increased control over health improvements. A patient's sense of positivity at having completed a PRP, and its impact on their subsequent health and well-being, was very apparent during the workshops. Patients stressed the importance of a future assessment of longitudinal effects of the programme (which this study did not cover in any detail). They found PRP professionals supportive, and discussed the relationships they made with others from the programme in a similar position to themselves. These relational links also affected their outlook on life and future health aspirations. Patients praised those putting on the programme vociferously and on numerous occasions, suggesting the value patients place on the above-mentioned proposition in all its aspects. Patients' views also indicated a new and positive outlook on on-going healthcare needs, and a commitment to a more independent approach to healthcare management. Patients valued this new belief in their physical and mental ability, and the way that this strengthened their relationship with others. Professionals stressed the importance of bringing patients to a greater understanding of their illness, a sentiment that was shared by patients and significant others. Even though attending the PRP had been daunting at first, patients quickly came to appreciate its benefits and the opportunities it offered to meet others in similar situations. It was simply a "life-saver" which came at a time when they were desperately in need of life improvement or, at the very least, sustainment. For many, the PRP had brought an ability to believe in this long-awaited change. [25]

*Physical health:* Learning how to breathe "properly" had a profound impact on patients, not only because breathing well was seen as vitally important to their health and quality of life, but also because it was something that needed to be learned. Patients retrospectively appreciated that this PRP was "perfectly right" to make them focus on their breathing and to bracket their other concerns, such as weight loss. Learning how to breathe was complemented by the PRP's relaxation component that included relaxation exercises and deep breathing exercises, which gave them a chance to control their anxieties and deal with panic attacks.

One striking facet of the PRP, for both patients and significant others, was the direct experience of health improvements, which proved a source of motivation, joy, and pride. Improvements to physical health translated into greater independence, both functionally and socially. A break in the cycle of inactivity engendered the patient's physical and mental strength. Patients, professionals, and significant others all stressed that the exercise regime was attuned to the patient's individual capabilities. Nevertheless, convincing patients to undertake exercise was challenging. Many patients felt embarrassed at first to undertake physical exercise routines alongside others that they perceived as either fitter or slimmer than themselves. Some found the exertion demanding, but as patients became familiar with the exercise regime and the demands of the programme they adjusted well and were able to allay their fears and embarrassment to a great extent, even joking about issues they once found awkward. [26]

*Mental health:* Bringing patients together in one space to take part in the programme was seen to have helped them to appreciate that they were not alone in their feelings and experiences. The PRP led to improved attitudes towards COPD, which found its fullest expression in terms of hopefulness for the future. Patients hoped to sustain their newfound gains with respect to their quality of life. Professionals hoped that the patients would continue their exercise regimes, and significant others hoped that their loved ones would stay as they are. The attitude of significant others also improved, insofar as they came to recognise that they risked falling into the trap of being "over-protective" of their loved ones, reinforcing the cycle of inactivity and dependency. Significant others emphasised how patients gained in "confidence" that came from being with others and doing things for themselves. Confidence was not simply the confidence "to do" everyday activities, but also the confidence "to be" themselves again. Patients spoke of a life transformed, and agreed that one of the main challenges was in keeping motivated and keeping going, not only during the PRP, which was difficult enough, but also thereafter. [27]

*The programme:* All groups explained that the patient had positive outcomes from completing the programme on a number of levels—physical, mental and social—but only if they attended for the full duration of each programme, which helped them to build up their confidence, cope better with life and understand their disease. Patients emphasised the collective experience of the PRP, while professionals emphasised the evidence-base for its efficacy, and the importance of a multidisciplinary approach and outpatient model. For professionals, the patient outcome was a key focus, with capacity, well-being, symptom control, and hospital admissions being measured. However, measurements were not taken in a qualitative way, until now. Despite some initial misconceptions among patients about the nature of the PRP, particularly with respect to the unexpected exercise regime, there were ambivalent opinions about whether more information should be provided. People suggested the idea of "exercise" and "gyms" could deter some patients from enrolling. Nevertheless, the embedding of exercises within daily activities was extremely effective, motivating and rewarding. Many patients welcomed follow-up and refresher sessions, along with more advice on embedding exercise within everyday life. Patients and significant others, whilst

often unclear about the nature of the waiting list, felt that those with serious conditions should be given priority and, being mindful of funding pressures, were adamant that the PRP was very good value for money. [28]

*Professionals and significant others:* Patients regarded the professionals as "caring" and "friendly". Patients felt that professionals treated them with "dignity" and "respect" and created a welcoming and safe environment for patients to feel "cared for" and "at ease". Having previously fallen "victim" to a "faceless NHS"<sup>1</sup>, patients re-gained an identity, both in their own eyes and in the professionals' eyes. Professionals were motivated by how patients valued their work, and enjoyed multidisciplinary teamwork. Limited resources (especially staff and space) constrained capacity, but did not unduly affect quality. Despite "time pressures" and waiting lists, patients valued professionals "having time for them". Sharing the experience with others was very important, although patients noted that there was a sense of intimidation and anxiety about exercising in groups, sometimes leading to poor attendance. While patients considered that general practitioners (family doctors) failed to understand their condition, PRP professionals had a full, almost visionary understanding, discussed in revolutionary terms: "a revolution of everyday life". Patients, to emphasise the way they felt about these health professionals' work on the programme, used strong terms, such as "revolution", stating PRP professionals had "revolutionised" their daily life. Patients often described significant others as "overprotective" and prior to the PRP, significant others described "feeling helpless", "terrified", and being in a state of constant "worry". However, significant others were now less anxious and overprotective, benefiting from the respite that the sessions afforded. They could also manage their own health more effectively from the vicarious learning of new breathing techniques and exercises. [29]

*Knowledge and education:* The PRP created a "learning environment", lasting many weeks after the PRP concluded, where patients better managed to cope with their illness. This PRP focused on three components: relaxation, physical exercise, and education. Professionals were keen to infuse knowledge and education to maximise the everyday benefit of these components and ensure medication, inhalers and other equipment were used effectively. Patients experienced greater understanding and control of their condition by learning about symptoms and "proper" breathing. The learning environment built confidence and encouraged "knowing their own bodies" and "learning their own physical capabilities". Professionals and significant others described patients' new knowledge and coping abilities as having impact beyond the patient. The role of significant others had changed, from newly acquired knowledge and skills. Patients were more prepared to take charge of medication and attempted more physically challenging activities demonstrating less reliance on others. Patients and significant others commented on the initial lack of knowledge regarding expectations of exercise and gym work that might provoke anxiety in prospective participants. [30]

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1 The National Health Service, or NHS, was founded in the United Kingdom in 1948 to provide a comprehensive range of health services funded through the Government's central taxation and national insurance.

*The future:* Everyone felt that sustaining the PRP into the future was essential. Everyone emphasised a plethora of benefits, directly attributable to the programme, including improved health outcomes, enhanced quality of life, fewer hospital admissions and less time spent in hospital and consequently financial savings for the NHS in the UK. Patients and significant others experienced the benefits for themselves, and were adamant about the vital nature of the service for others to enjoy. Professionals were confident that the PRP benefits could be clearly articulated to NHS managers, because there was a well-established evidence base for its clinical and financial efficacy. This was found to be especially true in the short-term: both for this particular programme and the model for pulmonary rehabilitation more broadly. However, there was perceived to be merit in extending the evidence-base into the medium-term and long-term, which clinicians had yet to do. Goal-setting and the use of charts to monitor weekly exercise progress could support a culture of self-motivation in patients. All groups agreed that positive outcomes went far beyond the timescale of the actual PRP. Furthermore, in the future, professionals wanted delivery to a wider patient cohort, in more areas as well as a programme for in-patients. [31]

## **5. Discussion**

This study has revealed overwhelming support for the PRP. This includes emphatic praise from all patients and significant others involved for the work and commitment of PRP professionals and PRP managers. There was a strong belief that the PRP had a positive impact, in the short and long-term. [32]

There was resounding enthusiasm from patients, taking part in the PRP. This could be seen by: increased patient activity, greater patient control, increased confidence, more willingness to self-manage medicines, and enhanced sense of group belonging. As a consequence, there was less reliance on significant others, which freed up significant others' time, which improved the physical health of significant others through learning activities and behaviour. A newfound sense of patient belonging is in line with the work of others (HALDING, WAHL & HEGGDAL, 2010) who indicate the value of engagement with people in similar situations as well as an emphasis on social integration for sharing knowledge and developing trust. [33]

For patients and significant others, these aspects really made a difference to their self-respect. However, they were concerned about benefits diluting over time and wanted refresher courses and other approaches to ensure gains were sustained. Indeed, extending services and offering the PRP to wider patient groups was deemed by all to be particularly beneficial for patients and the NHS alike, reducing inpatient stay and dependency on hospital staff. This is a view that is shared by others (HARRIS et al., 2008). [34]

Patients recognised that change in the long-term would be dependent on greater resource allocation, a better understanding of patient commitment and improved patient adherence to new exercise and lifestyle regimes. Professionals also commented on the long-term implications of reduced exacerbations and hospital

stays, and enhanced social and physical function, echoing the views of others (HARRIS et al., 2008). CAMP et al. (2000) and GRIFFITHS et al. (2000) both reinforce the view that PRP will have a positive impact on patient QOL, if the programme can encompass training, education and coping strategies in one package. Others have written about quantitative QOL measures alone, rather than in combination with qualitative assessment. CAMP et al. (2000) for example have noted extensive improvement to physical and emotional function. The study presented in this article goes one step further, by also *explaining* what this means for patients, professionals and significant others, particularly in terms of social interaction, task performance and enhanced physical capability. [35]

### **5.1 Strengths of the study**

This approach to data capture and data analysis is new to the COPD field, and the detailed insights in this site-specific, mixed method examination indicate the major strengths of the study, which could be expanded to other locations. Mixed method approaches can enhance understanding and add validity by offsetting weaknesses of quantitative or qualitative methods used in isolation (CRESWELL & PLANO CLARK, 2011). In addition, each method can be used corroboratively to add detail and depth from the findings revealed through other methods. In this study, the team worked closely with all healthcare professional disciplines delivering the PRP. A small number of refusals to participate from patients and significant others indicates minimal selection bias. [36]

An additional strength of the study lies in the fact that the PRP was itself based on a proven model (GRIFFITHS et al., 2000). In this model, hospital data measured baseline health to relate QOL and healthcare utilisation a year prior to the PRP. The findings suggest statistically and clinically important patient benefits that can be maintained over a six-month period, reverting back to baseline in those surviving one year. [37]

### **5.2 Limitations of the study**

Limitations of the study include region and site-specific findings, although the demographics are typical for patients attending a PRP based within the UK. Furthermore, the study did not include patients undergoing PRP for conditions other than COPD and future work with more patients, across disease types, would enable a retesting of the methodology more broadly to improve validity. [38]

## 6. Conclusion

To advance the work that considers PRPs in this field, we summarised our findings in the following seven observations:

1. Account should be taken of patient, significant other and professional views in combination, rather than as discrete constituencies.
2. Consideration should be given to the value of methodological innovation, including consultation workshops, for in-depth insight in order to advance the field of respiratory medicine.
3. Awareness of patients' almost evangelic belief and pride in the PRP's outcomes and patient support for PRPs should be factored in to future PRP development and testing. By recognising patient "buy-in", and accommodating patient expectation, there is an increased chance of sustaining high-quality PRPs.
4. Programmes should be prioritising those most in need of support, in view of scarce resource availability, as altruistically advocated by patients and significant others in this study. This would ensure that flagship PRPs could thrive.
5. Major benefits of PRPs should be more widely recognised, including: greater patient control, motivation and independence, patients' own desire for greater levels of fitness and willingness to self-manage healthcare following PRP; as well as the knock-on effects on significant others.
6. The NHS should commit appropriate resources to these services leading to financial and staffing savings in the long-term.
7. Whilst long-term benefits to patients are currently not measured qualitatively, there is overwhelming support and zeal for the programme, which was described in almost "revolutionary" terms, that should not go unrecognised. This support indicates an embodied sense of hope in the future for this disease group. [39]

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## Appendix: Interview Schedule for Session 1

### Workshop with patients

1. How would you describe the Programme to another person?
2. Before the Rehabilitation Programme began, what did you hope would be its benefits in terms of your health-related quality of life (HRQL)? (Physical health, mental health, social functioning, emotional functioning)

3. Did the Programme live up to your expectations?
4. Having now completed the Programme have there been any unexpected benefits or downsides? (Physical function, mental, social, emotional; how behaving now?)
5. Before you entered the Rehabilitation Programme how did COPD effect your quality of life and physical ability to function?
6. Do you think the effects of the Programme will last in the longer-term and if so, why? (Barriers, different barriers for different patients)
7. Were there any disadvantages to participating in the Programme?
8. What sort of support did you receive from health professionals involved? (What support is needed?)
9. What sort of support, if any, did you receive from other patients? (Ongoing contact? What support is needed?)
10. During the Programme what was the response of family members and/or friends? (Affected relationships?)
11. Can you suggest improvements to the Programme for future patients or health professionals?

#### **Workshop with significant others/friend/carer of COPD patient**

1. What do you know about the COPD Rehabilitation Programme and could you describe it?
2. Before the patient entered the Programme how did COPD effect their quality of life and physical ability to function?
3. Before the patient started the Programme what did you think would be the benefits/down sides for the patient? (Physical health, mental health, social functioning, emotional functioning)
4. Were you involved in any of the initial meetings between the patient and health professionals? (Or receive information about the Programme? Ongoing support?)
5. Having completed the Programme what do you see as the benefits/down sides for the patient? (Physical function, mental, social, emotional)
6. Did the patient describe the Programme to you as having lived up to their expectations?
7. During the Programme, did the patient ask for your support or others' support?
8. Did the Programme affect your relationship with the patient (Others relationships?)
9. Do you think the effects of the Programme will last in the longer-term and if so, why?
10. Is there anything else that you or the patient will gain from the Programme in the longer-term?



## Workshop with health professionals

1. How would you describe the COPD Pulmonary Rehabilitation Programme?
2. What support do you and other health professionals provide during the Programme?
3. What are its benefits for patients in terms of their health-related quality of life? (Physical health, mental health, social functioning, emotional functioning)
4. Following your involvement, have you noticed any unexpected benefits for patients?
5. Are there any disadvantages to the Programme?
6. Do you think the Programme lives up to patients expectations? (Examples to support view)
7. Do the effects of the Programme last in the longer-term and if so, why?
8. Are you satisfied with the level of service delivery and patient/carer support?
9. Do patients receive support from people other than the health professionals involved?
10. What do you gain from your involvement in the Programme?
11. Can you suggest improvements to the Programme for future patients?

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