Abstract P52 Table 1 Mean baseline scores and mean changes for Hospital Anxiety and Depression Scale, Self-Reported Chronic Respiratory Questionnaire, Incremental Shuttle Walking Test (ISWT) and Endurance Shuttle Walk Test (ESWT) for usual care and self-management groups

	Self-managem	ent	Usual GP care	
Measure	Baseline	Mean change (95% CI)	Baseline	Mean change (95% CI)
Anxiety	7.41	-1.76 (-0.10 to 3.23)*	4.74	0.84 (2.55 to 0.87)
Depression	4.88	-0.35 (0.91 to 3.43)	3.95	0.53 (1.37 to 0.31)
Dyspnoea	3.31	0.74 (1.23 to 0.25)**	3.25	0.41 (0.87 to 0.04)
Fatigue	4.13	0.34 (0.97 to 0.29)	4.60	0.16 (0.40 to 0.72)
Emotion	4.84	0.51 (1.05 to 0.03)	5.22	0.23 (0.08 to 0.53)
Mastery	5.48	0.30 (0.81 to 0.22)	5.62	0.10 (0.24 to 0.44)
ISWT (m)	325.29	37.65 (70.44 to 4.85)*	342.63	-28.42 (-2.60 to 54.24)*
ESWT (s)	227.00	358.59 (506.65 to 210.52)***	369.95	34.53 (98.32 to 29.27)

^{*&}gt;0.05; **>0.01; ***>0.001 within subjects.

This shows that it is feasible to deliver a self-management package in primary care as a stand alone manual, with significant improvements demonstrated in dyspnoea, exercise performance and anxiety.

P53

PULMONARY REHABILITATION USING THE SPACE (A SELF-MANAGEMENT PROGRAMME OF ACTIVITY, COPING AND EDUCATION) MANUAL AT HOME: A RANDOMISED CONTROLLED TRIAL

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Pulmonary rehabilitation is an established intervention for patients with chronic obstructive pulmonary disease (COPD), however capacity across the UK is low. The traditional model of rehabilitation is 6–8 weeks of supervised exercise and education. We have developed a self-management manual for COPD (SPACE: A Self-management Programme of Activity, Coping and Education). If a self-managed pulmonary rehabilitation programme is effective, alternative forms of pulmonary rehabilitation may become more widely available. The aim of this study is to determine the effectiveness of a self-management programme against conventional rehabilitation.

Participants with COPD were recruited following a standard pulmonary rehabilitation assessment and randomly allocated to either a 7-week conventional rehabilitation course or self-managed rehabilitation using the SPACE manual. The primary outcome measure was peak exercise performance (Incremental Shuttle Walking Test (ISWT)) measured at initial assessment and 7 weeks. Other outcome measures were Endurance Shuttle Walk Test (ESWT), Self-Reported Chronic Respiratory Questionnaire (CRQSR) Dyspnoea Domain and the Medical Research Council

Dyspnoea Scale (MRC). 62 patients were recruited and allocated to conventional rehabilitation (n = 29; mean (SD) age 67.93 (7.47); forced expiratory volume in 1 s (FEV $_1$) 1.38 (0.52); body mass index (BMI) 26.27 (5.91); 18 men) or self-management (n = 33; mean (SD) age 66.75 (8.00); FEV $_1$ 1.16 (0.36); BMI 26.77 (5.76); 2 men). Patients were re-assessed at 7 weeks and paired t tests were performed for all outcome measures.

There were statistically significant improvements for both conventional rehabilitation and self-managed rehabilitation in ISWT with mean changes of 54.48 ± 89.06 and 40.30 ± 70.02 , respectively. There were also statistically significant improvements for ESWT, CRQ-SR Dyspnoea and MRC in both groups; mean changes in conventional rehabilitation being 500.62, 0.64 and 0.80, respectively, and in self-managed rehabilitation being 331.33, 0.77 and 0.71, respectively (table 1). There were no statistically significant between-group differences found in ISWT, ESWT, CRQ Dyspnoea and MRC (p>0.05).

Participants who completed both conventional rehabilitation and a self-management programme showed significant improvements in exercise performance and perceived dyspnoea. There were no significant differences between the outcomes for each group. This shows that a self-managed rehabilitation programme is an effective alternative to conventional rehabilitation.

P54

COPD PATIENTS' BELIEFS AND EXPECTATIONS OF PULMONARY REHABILITATION

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Introduction The effectiveness of pulmonary rehabilitation (PR) for chronic obstructive pulmonary disease (COPD) is tempered by the effect of time. Little is known about the role of patients' beliefs and expectations in outcome response and in maintenance. The aim of

Abstract P53 Table 1 Mean baseline and mean changes for Incremental Shuttle Walking Test (ISWT), Endurance Shuttle Walk Test (ESWT), Chronic Respiratory Questionnaire Self-Reported (CRQ-SR) Dyspnoea Domain and MRC for conventional rehabilitation and self-management groups

	Conventional rehabilitation		Self-managem	ent
Measure	Baseline	Mean change (95% CI)	Baseline	Mean change (95% CI)
ISWT	277.24	54.43 (88.36 to 20.60)*	253.33	40.30 (65.13 to 15.47)*
ESWT	225.00	500.62 (656.90 to 344.32)**	257.02	331.33 (483.86 to 178.81)**
CRQ-SR Dyspnoea	2.61	0.64 (1.11 to 1.72)*	2.14	0.77 (1.19 to 0.34)*
MRC	3.40	-0.80 (-0.48 to 1.12)**	3.19	-0.71 (-0.35 to 0.07)**

^{*&}gt;0.01; **>0.001.

this study was to explore in-depth COPD patients' beliefs and expectations of PR.

Methods Purposive homogenous sampling was employed to recruit prospective COPD patients referred to an outpatient PR. In-depth qualitative interviews were conducted before PR and Interpretative Phenomenological Analysis (IPA) was the analytical method.

Results 15 COPD patients were interviewed (10 women, mean (SD) age 70.2 (9.3) years, forced expiratory volume in 1 s (FEV₁)% predicted 56 (12)%, endurance shuttle walking test (ESWT) distance 216 (155) m; MRC all >3). In terms of participants' expectations and beliefs about PR, the first theme to emerge was "a life worth living". Both psychosocial and functional improvements were equally desired outcomes from attending PR. Hope for a more meaningful life gave rise to strong intentions to attend PR. PR was often viewed as a learning opportunity. A second theme which emerged was "PR as an opportunity for a challenge". ESWT was generally viewed as a positive challenge and provided a sense of achievement, often lacking in patients' daily lives. Overall, patients had realistic expectations of the structure and content of PR, informed by the assessment, referral invitations and recommendations from others. Few patients mentioned a need to continue physical activity after PR. For a smaller group of patients, "barriers to attending PR" was a third theme. The main issues were doubts about ability and PR effectiveness, dislike of groups, a confusing PR invitation and lack of family support.

Conclusion COPD patients expect functional and psychosocial benefits from attending PR, which is compatible with the multi-disciplinary approach. While most people welcome PR as a challenge, others have early apprehensions. Interestingly, few patients spoke of the need to continue physical activity on completing PR. These findings are the first in a larger study examining the trajectory of patients' beliefs over time, which may help to inform the development of biopsychosocial maintenance approaches in the future.

P55

LARGE-SCALE COMMUNITY PULMONARY REHABILITATION: MORE THAN A QUESTION OF NUMBERS

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Introduction BreathingSpace (BS) is a community-based facility dedicated to the assessment and management of patients with COPD. One of its original ideals was to deliver pulmonary rehabilitation on a large scale for the local community. We report on its first 2 years of activity.

Service Design Patients can be referred for pulmonary rehabilitation by any healthcare professional or carer and can self-refer. They are initially assessed by the BS nursing team and, if appropriate, referred to the BS therapy team. Between two and four whole time equivalent (WTE) physiotherapists supported by four band 4 support workers (who also provide the smoking cessation service), one WTE occupational therapist and some administrative support

has been available to deliver high intensity (HIP), low intensity (LIP), activities of daily living (ADL) programmes and maintenance classes. The aim was to provide a programme of 16 sessions but to accept a minimum of 12 sessions as a marker of satisfactory completion. HIP, LIP and ADL programmes are run by therapists with support workers supporting these classes and running the maintenance sessions. Transport is provided free of charge to attendees.

Outcomes Between June 2007 and 2009, 1004 patients were referred to the therapy team following clinic assessment, of which 804 agreed to attend programmes. Rehabilitation programmes have been successful with completion rates for HIP and LIP of 84% and 83%, respectively. Endurance walking times increased in both HIP (mean 6.06 to 17.32 min) and LIP (mean 3.40 to 11.20) programmes. 49% HIP and 42% LIP have continued to attend weekly maintenance classes following completion of their rehabilitation programmes (table 1).

Discussion Pulmonary rehabilitation is possible to deliver on a large scale in the community. The effectiveness of this particular programme in terms of completion rates, maintenance attendance and endurance results may in part be due to the resources put into ensuring patient commitment and compliance with programmes. Commissioning guidance suggests that more can be done for less, and we would advise caution to tenderers wishing to put quantity pulmonary rehabilitation above quality pulmonary rehabilitation.

P56

PATIENT PREFERENCES FOR QUALITY OF LIFE MEASURES IN PULMONARY REHABILITATION: BREATHING PROBLEMS QUESTIONNAIRE SHORT VERSION (BPQ-SV) VS CHRONIC RESPIRATORY QUESTIONNAIRE SELF-REPORT (CRQ-SR)

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Introduction Choice of outcome measure is often determined by ease of delivery, scoring, familiarity and interpretation of scores, with patient preference not always taken into account. In our PCT we are attempting to harmonise care across the PCT, including the use of outcome measures. Both the Chronic Respiratory Questionnaire Self-Report (CRQ-SR) and the Breathing Problems Questionnaire Short Version (BPQ-SV) are validated simple self-completed disease-specific quality of life measures requiring no software to score. Both have been shown to be equally sensitive to change, 12 making either suitable for a busy clinical service.

 $\pmb{\mathsf{Aim}}$ To determine patients' preferences between the CRQ-SR and BPQ-SV.

Method Between April and June 2009, 83 patients across the PCT completed both the BPQ-SV and the CRQ-SR before PR. Patients were asked to complete a simple questionnaire rating preference for ease of completion, accuracy of information relayed and overall preference.

Abstract P55 Table 1

	HIP	LIP	ADL
Total invited	336	293	175
Mean (range) age (years)	66 (39-86)	69 (44-91)	74 (38–93)
Attended min 1 session	237 (70%)	201 (69%)	
≥12 sessions completed	198 (84%)	166 (83%)	
Commenced maintenance post rehabilitation	117 (49%)	85 (42%)	
Mean (range) FEV ₁ (%pred)	49 (16-104)	46 (13-115)	47 (12-91)
Mean (range) ESWT-pre (min)	6.06 (1.08-20.20)	3.40 (0.52-11.20)	
Mean (range) ESWT-post (min)	17.32 (1.03-54.30)	11.20 (1.00-35.00)	

ADL, activities of daily living programme; ESWT, endurance shuttle walking test; FEV₁, forced expiratory volume in 1 s; HIP, high intensity programme; LIP, low intensity programme.

Abstract P56 Table 1

	Preference		
	BPQ-SV N (%)	CRQ-SR	No preference N (%)
Question		N (%)	
Ease of completion	61 (73)	7 (8)	15 (18)
Accuracy of information	37 (45)	39 (47)	7 (8)
Overall preference	53 (64)	20 (24)	10 (12)

BPQ-SV, Breathing Problems Questionnaire Short Version; CRQ-SR, Chronic Respiratory Questionnaire Self-Report

Results The results are shown in table 1.

Conclusion Overall, patients strongly preferred the BPQ-SV and found it easier to complete. This may be important when considering the literacy levels and socioeconomic profiles of the

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PATIENTS WITH SEVERE COPD REFERRED FOR PULMONARY REHABILITATION WHO NEVER ATTEND: USE OF HOSPITAL RESOURCES AND RISK OF DEATH

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Introduction Pulmonary rehabilitation (PR) improves quality of life. Failure to complete programmes is a well recognised problem, but there is also a cohort of patients who accept referral but never even begin. In this study we have attempted to characterise this group with a view to providing an alternative service for them.

Methods Case notes were retrospectively reviewed for all hospital patients referred for PR from January to December 2007. Only patients who completed PR in that year and patients who failed to attend even one session were included. Demographic data, forced expiratory volume in 1 s (FEV₁), MRC Dyspnoea Score (MRCDS), long-term oxygen therapy (LTOT) and smoking status were recorded at time of referral and again 1 year later from GP or hospital records. Emergency department (ED) attendances, hospital admissions and utilisation of community resources (matrons, respiratory/heart failure teams) were documented for the year following PR referral.

Results 39 patients (18F:21M, mean \pm SD age 66.5 ± 10.4 years, 31/ 39 (79%) chronic obstructive pulmonary disease (COPD)) completed PR in 2007. 47 patients accepted PR referral but never attended. There was no significant difference in age $(69.9 \pm 11.1 \text{ years})$, gender (17F:30M), respiratory pathology (43/47 (91%) COPD) or disease severity in the latter group (mean \pm SD FEV_1 1.1 \pm 0.5 (n = 43), MRCDS 3.6 \pm 0.8) compared with the group who completed PR (FEV₁ 1.1 ± 0.5 , MRCDS 3.3 ± 0.7), although fewer patients in this group smoked (7/39 (18%)) or used LTOT (3/ 36 (8%)) compared with the PR non-starters (16/47 (34%) smokers, 6/37 (16%) on LTOT). In the year following PR referral, patients who never attended used more community services (15/47 (32%)), had more ED attendances (40), significantly (p = 0.05) more hospital admissions (28 using 219 bed-days) and a significantly (p<0.05) higher death rate 11/47 (23.4%)) compared with patients who completed PR who used less community services (4/39 (10%)), had 16 ED admissions, 8 hospital admissions/113 bed-days and 1/39 (2.5%) deaths.

Conclusion These data suggest that patients with severe disease who accept PR referral but never attend are a vulnerable group at increased risk of hospital admission and high risk of death and therefore most in need of PR intervention. A novel alternative possibly home-based approach to offering exercise, self-management skills and advanced care planning may need to be provided.

P58 NUTRITIONAL ASSESSMENT IN PULMONARY REHABILITATION

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Background Pulmonary rehabilitation has established itself as a mainstay of management for patients with chronic respiratory disease, addressing functional, dietary and behavioural elements. A body mass index (BMI) at either extreme is associated with a worse prognosis, and a dietetic input is essential to the multidisciplinary team. However, a low skeletal muscle mass (fat-free mass, FFM) is more prognostic² and may exist in the presence of a normal BMI (hidden FFM). We explored the utility of adding bioelectric impedance analysis to our rehabilitation assessment.

Methods Consecutive patients entering pulmonary rehabilitation from the end of October 2007 onwards were assessed at the start and completion of pulmonary rehabilitation. Standard anthropometry including BMI was performed. In addition, FFM and the height squared ratio (FFMI) were assessed using bioelectrical impedance (Tanita BC-418MA). The course has previously been described elsewhere.3

Results Of 187 patients (93 men), mean (SD) age 67 (10) years, the BMI was 27.2 (6.4) kg/m²; 21 (11%) had a low BMI (<20 kg/m²) and 50 (27%) were obese (>30 kg/m²). FFMI was available in 87% (163) of subjects. In total, 33/163 (20%) had a low FFMI (12 men). Of those with a low BMI, 16/17 had a low FFMI (<16 kg/m² in men, <15 kg/m² in women), but a further 17 subjects had a low FFMI with a BMI 20-30 kg/m² (hidden FFM). With rehabilitation (n = 161) there was a trend for weight gain in those with a low BMI and weight loss in those with an obese BMI (p = 0.01 between groups (ANOVA)), but with marked variation. Those with a low FFMI had similar incremental shuttle walk test at outset and gain with rehabilitation compared to those with a maintained FFMI as well as having a similar dropout rate.

Conclusions Bioelectrical impedance identifies patients with hidden skeletal muscle mass loss not otherwise identified by BMI alone, thus allowing targeted dietetic focus in the multidisciplinary pulmonary rehabilitation setting focusing on nutritional optimisation. The short-term changes in weight with rehabilitation need to be continued with lifestyle modification.

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EVALUATION OF THE SURREY INFORMATION ON FUNCTION TOOL (SIFT) AS A FUNCTIONAL OUTCOME MEASURE FOR **PULMONARY REHABILITATION**

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The Surrey Information on Function Tool (SIFT) was developed as a functional outcome measure for pulmonary rehabilitation (PR) as other similar tools were not deemed time efficient. We aimed to evaluate its validity against the Canadian Occupational

Abstract P59 Table 1 Mean (SD) scores for the Surrey Information on Function Tool (SIFT) and the Canadian Occupational Performance Measure (COPM) pre and post pulmonary rehabilitation (PR) (n = 52)

	SIFT F	СОРМ Р	SIFT C	COPM S
Pre PR	4.47 (1.18)	4.54 (1.19)	3.31 (1.70)	3.87 (1.75)
Post PR	6.19 (1.68)*	5.99 (1.63)*	6.27 (2.29)*	6.36 (2.11)*
Change	-2.45 (2.07)†	-1.44 (1.70)†	2.91 (2.37)‡	1.70 (1.61)‡

^{*,†,‡}defined in text.

Performance Measure (COPM) pre and post PR, and its sensitivity to change with PR. Both tools have two components: SIFT Function (F) and Contentment (C); COPM Performance (P) and Satisfaction (S). Patients rate chosen activities.

Patients attending PR and who consented (n = 52) completed both SIFT and COPM in random order pre and post PR. Randomisation was by sealed envelopes.

 $\begin{picture}(60,0)\put(0,0){V alidity} SIFT F correlated well with COPM P (Pearson correlation).} \label{fig:picture}$ $(r) = 0.53\dagger$, p = 0.000) and SIFT C with COPM S $(r = 0.63\ddagger$, p = 0.000, table).

Sensitivity to change Both components of both tools were highly sensitive to change (paired t test $p = 0.000^*$, table 1) with no statistically significant difference between the two tools.

Conclusion SIFT is a valid, sensitive and simple functional tool to use for PR.

Clinical issues in paediatric lung disease



P60 A REGIONAL SURVEY OF PAEDIATRIC CONSULTANTS' PRACTICES AND ATTITUDES IN THE MANAGEMENT OF SPINAL **MUSCULAR ATROPHY TYPE 1**

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The management options for spinal muscular atrophy (SMA) are changing with an increase in the use of non-invasive and invasive ventilation. However, there are few empirical data to support the practice of long-term ventilation in improving quality of life in these patients. Without active respiratory management, children with SMA usually die within the first 2 years of life. We designed a survey to assess current attitudes and practices in the management of this condition in a single geographical region of the UK.

Methods In November 2008 a web-based anonymous survey was sent to all paediatric consultants within the region who would have potential contact with a child with SMA. Following a brief clinical scenario of an infant with SMA type 1, a number of management options were suggested regarding general health care, antibiotics for infection, feeding options, immunisations, ventilation for acute illness and long-term home ventilation. For each option, respondents were asked if they would (a) not discuss, (b) discuss but not recommend or (c) recommend the intervention.

Results 72% (133/185) of consultants completed the survey. They were representative of the surveyed population in terms of place of work and specialty practice. 83% of respondents would recommend nasogastric feeding, 79% oral antibiotics and 39% intravenous antibiotics during infections. 73% would recommend influenza and pneumococcal vaccination and 44% would recommend RSV prophylaxis. Non-invasive ventilation (NIV) would be recommended for the acute management of a respiratory infection by 52% but only 14% would recommend intubation and ventilation, although 82% said they would discuss this with the family. A high proportion of respondents would discuss long-term ventilation with NIV (72%) or tracheostomy (73%) ventilation but only 18% would recommend NIV and 8% would recommend long-term tracheostomy ventilation. Recommending referral to specialist services varied by specialty; 83% to palliative care, 79% to neurology and 65% to respiratory medicine.

Conclusions This preliminary survey suggests a variation in what interventions are recommended to families of children with SMA type 1 but indicates that a high proportion of respondents would discuss the majority of management options with the family.

IMPACT OF PHYSIOLOGIST SUPERVISION ON THE QUALITY OF RESPIRATORY SLEEP STUDIES IN CHILDREN

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Introduction The diagnosis of sleep-disordered breathing in children can be made from assessment of gas exchange (specific but insensitive) or by multichannel respiratory sleep studies. The current UK provision of complex respiratory studies is low and many units do not have supervised or attended studies. Ideally, interpretation of studies requires continuous signals from all channels; however, data are frequently suboptimal. In our unit sleep physiologists have traditionally set up the sleep studies on children in the evening and the studies have then been unsupervised. Recently we have moved to having sleep physiologists supervising/attending studies overnight. We aimed to assess the impact of this change.

Method 80 respiratory studies on children aged 0–17 years performed on an Alice 4 system between April 2008 and July 2009 were retrospectively analysed, 40 studies before and 40 studies after overnight supervision was introduced. Scoring was done using American Sleep Disorders Association standard criteria. Our routine respiratory study consists of 11 separate channels including measures of airflow, gas exchange, bands and movement. Any channel that was lost for more than 30 min was judged to have

Results 27/40 (68%) unsupervised studies had at least one lead that failed compared with 6/40 (15%) supervised studies (p<0.0001). The mean number of failed channels in the unsupervised studies was 1.05 (SD 0.96), significantly greater than a mean 0.18 (SD 0.45) of the supervised studies (p<0.001). 15/40 of the unsupervised studies had one lead that failed, 8/40 had two leads that failed and 2/40 had three or more failed leads, compared with 5/40 of the supervised studies with one failed lead and 1/40 with two leads that failed. The most common of the channels to fail were the thermister (10/40 unsupervised, 2/40 supervised), end tidal CO₂ (8/40 unsupervised, 4/40 supervised) and thoracic bands (6/40 unsupervised, 0/40 supervised).

Conclusion This study demonstrates a significant improvement in the quality of respiratory sleep studies following the introduction of overnight physiologist supervision. Significantly fewer data were lost, particularly those assessing airflow, therefore reducing the need for repeat studies and giving greater confidence in interpretation of respiratory data.