

# How Do Patients' Needs For Information About COPD Change Over Time: An Observational Cohort Study

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## Research Article

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# Abstract

**Background:** This Swedish observational cohort study aimed to assess changes in patients' perceived needs for information about COPD over 18 months and how these changes related to changes in patient characteristics.

**Methods:** Data were obtained from 293 randomly selected primary care patients with COPD in GOLD stages 2-3. The Lung Information Needs Questionnaire (LINQ) was used to assess patients' information needs at baseline and 18 months. Self-reported, descriptive patient data and spirometry results were collected.

**Results:** Although the mean total LINQ score did not change between baseline and follow-up, 43.3% of the patients reported reduced and 56.7% increased or unchanged information needs. Reduced information needs were mainly associated with onset of pulmonary rehabilitation (OR=2.26 [95% CI 1.05-4.86]). Patients in a stable phase of COPD with no recent exacerbations tended to report greater needs than those with an unstable, deteriorated COPD.

**Conclusion:** Patients' information needs covary with current clinical status, so care providers should continuously be vigilant about offering patients support and education.

**Trial registration:** Clinicaltrials.gov, 10 August 2014, Identifier NCT02213809.

## Background

Chronic obstructive pulmonary disease (COPD) is a major cause of morbidity and mortality worldwide (1). Smoking cessation and prevention of acute exacerbations improve prognosis, whereas optimized medications and pulmonary rehabilitation reduce symptoms (2). Comorbidities worsen health status and prognosis and increase healthcare costs (3, 4).

Core components of person-centered care include regarding each patient as a person with physical, emotional, and social needs (5). Meeting these needs promotes health. Delivering information, education, and support that are based on patient's subjective experiences and needs can decrease anxiety and increase self-efficacy, health-related quality of life, and exercise capacity (6, 7). It can also lead to fewer unscheduled physician visits, hospital admissions, and days in the hospital (8). Becoming proficient in self-management is a cornerstone of living with a long-time condition such as COPD. For patients to master self-management of COPD, the information provided by health care professionals must be appropriate, individualized, and sufficient, and the patient must be motivated to learn more about the disease (9). In Sweden, the responsibility for informing and educating patients about COPD and self-management is usually shared by general practitioners (GPs), nurses, and physiotherapists, who often build a specific, patient-centered COPD care team. A 2014 study showed that patients at primary health care centers (PHCCs) with asthma/COPD teams had fewer unscheduled consultations with physicians, hospital admissions, and days in the hospital, which led to lower healthcare costs than at PHCCs without

such teams (8). An optimal patient-doctor consultation should also include educational aspects to meet patients information needs and thus support patient's self-management skills (10).

The current study is a part of a larger study (the PRIMAIR study, Stockholm, Sweden, 2014–2017), a pragmatic cluster randomized controlled trial about an educational intervention about COPD to GPs at 24 PHCCs (11). We have previously shown that relatively short educational interventions for GPs led to improvements in GPs' levels of knowledge about COPD (12, 13). At baseline, patients of the participating GPs reported substantial needs for more information about their COPD (14). These needs were assessed with the validated Lung Information Needs Questionnaire (LINQ) (15, 16). High continuity in GP-patient relationships was strongly associated with low information needs (14).

Our current study aimed to evaluate what the changes of patients' perceived needs for information about COPD are from the time before the GPs' education (baseline) to 18 months after the end of the education, and associations of these changes with patient characteristics.

## Methods

The current study used patient data from the PRIMAIR study. PRIMAIR's study protocol included a detailed description of its methodology and educational interventions (11). The current study used baseline and 18-month patient outcome data and has been written in accordance with the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies for cohort studies (17).

Prior to patient enrollment, all PHCC managers, GPs, and patients provided written informed consent to participate in the study. The study was approved by the Regional Ethical Review Board of Stockholm (ref 2013/232 – 31/5). It was registered at [www.clinicaltrials.gov](http://www.clinicaltrials.gov) on 10 August 2014, Identifier NCT02213809. The first participant was enrolled on 14 August 2014.

## Patient recruitment

Study enrollment for the parts of PRIMAIR that involved patients took place in 2014. PRIMAIR aimed to study the effects of GPs' education on both educational (GP-related) and clinical (patient-related) outcomes. According to the power calculation of PRIMAIR, a minimum of 460 patients divided in two study arms were needed to study two educational methods. However, in the current study, which is a part of the larger PRIMAIR-study, we regarded all the eligible patients as one cohort. This was because we had previously learned that PRIMAIR's post-intervention results regarding LINQ scores were independent of the type of educational intervention the GPs had received (18).

Eligible patients had a spirometry-confirmed ICD-10 diagnosis of COPD (J44.0-J44.9) in severity stages 2 or 3 according to the Global Initiative for Chronic Lung Disease (GOLD) 2013 definition of moderate or severe COPD (FEV1 30–79% of predicted) (19). To meet the needs of the power calculation for PRIMAIR, 957 randomly selected patients, 40 to 45 per PHCC, were invited to participate. Patients were asked to

complete a questionnaire (11) at baseline and after 18 months. The LINQ (15) was included as a part of this questionnaire. The patients included in the current cohort study were those in the PRIMAIR study population who replied to all the questions in the LINQ both at baseline and at the 18-month follow-up.

The LINQ has been designed to assess patients' individual needs for information about COPD and thus help health care professionals plan and individualize patient education. It consists of six domains: "Disease knowledge," "Medication," "Self-management," "Smoking," "Exercise," and "Diet." The minimum score per domain is 0, and the maximum varies between 2 and 6, depending on the domain. The maximum possible total score is 25. The higher the total score, the greater the respondent's perceived requirements for information about COPD. The informal MCID in the LINQ scores is 1 point (16).

Additionally, the patient questionnaire provided information about the patients' exacerbations, treatments, smoking habits, weight/height, comorbidities, health care contacts, and education. Validated questionnaires were used to assess patients' symptoms and health status, the Clinical COPD Questionnaire (CCQ) (20), the COPD Assessment Test (CAT) (21), and the modified Medical Research Council dyspnea scale (mMRC) (22) were included. Lung function measures, age, and gender were collected from patients' medical records.

## Statistical analysis

We analyzed the data in two sequences: first for the study population as a whole and then for four approximately equal size subgroups determined by the levels of their information needs (i.e. LINQ total scores) at baseline. Summary statistics such as means, proportions, and measures of dispersion were computed using standard parametric methods. McNemar's test was used to analyze differences in proportions over time. Paired t-test was used to analyze differences in continuous data over time. Logistic regression was used to analyze variables (e.g., patient characteristics, LINQ scores at baseline, CAT/CCQ/mMRC scores, exacerbations, medications, and contacts with care professionals) associated with changes in the LINQ scores. After a preliminary analysis in a univariate model, variables with a  $P$  value  $< 0.05$  and clinical importance were entered into a multivariable model in which  $P$  values  $< 0.05$  indicated statistical significance. We then performed a binomial logistic regression analysis with "a lower total LINQ score at 18 months than at baseline" (i.e., reduced information needs over the study period) as the response variable.

The statistical analysis was performed using SPSS software (IBM Corp. Released 2013. IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY: IBM Corp.).

## Results

At baseline, 57% (n=542) of the invited patients agreed to participate in PRIMAIR. At the 18-month follow-up, 78% (n=425) of the initial participants replied, of whom 69% (n=293) completed the LINQ both at baseline and after 18 months. Non-responders to the LINQ were older than responders (73.4 years vs. 71.1 years,  $P=0.009$ ) and more often lacked a specific, assigned GP at their PHCC (63.2% vs. 75.6%,

$P=0.012$ ). The non-response rate was independent of gender, lung function, smoking status, medications, contacts with COPD nurses and/or physiotherapists, level of education, and symptoms/health status (CCQ/CAT/mMRC scores).

## **Analysis of the study population as a whole**

### *Patient characteristics at baseline and over time*

Table 1 shows the main baseline characteristics of the 293 participants who completed the LINQ both at baseline and at 18 months. A subanalysis by gender (not shown in Table 1) revealed that women (57%) had smoked less than men (number of packyears 30.7 vs. 39.2,  $P=0.001$ ), and more women than men had depression and/or anxiety (27.1% vs. 8.7%,  $P=0.001$ ). Women also had a lower level of education than men (9 years or less, 62.9% vs. 45.9%,  $P=0.005$ ). There were no gender differences in lung function measures, medications, current smoking status, comorbidities (other than depression and/or anxiety), or patterns of contacts with health care professionals (GPs, COPD nurses, physiotherapists).

Table 2 shows the changes in patients' smoking intensity, exacerbations, body mass index, comorbidities, health status, medication, and care provider contacts over the 18-month study period. A total of 6.5% ( $n=19$ ) of the patients had quit smoking ( $P<0.001$ ), and 3.4% ( $P=n.s.$ ) had resumed smoking during the study period. The prevalence of daily smokers was 30.0% at baseline and 27.0% at 18 months ( $P=n.s.$ ). The proportion of patients who had consulted a physiotherapist increased from 11.9% to 17.4% ( $P=0.040$ ), and patients who reported having an assigned GP decreased from 75.6% to 65.3% ( $P=0.001$ ). The proportion of patients who had seen a COPD nurse remained the same over time (39.2% vs. 41.1%,  $P=n.s.$ ).

### *Changes in LINQ scores*

The mean total LINQ score of the 293 participants did not change over time (10.8 points at baseline vs. 10.9 points at 18 months, that is, 43.5% of the maximum 25 points) (Figure 1).

A logistic regression analysis was performed for the whole study population, with "a lower total LINQ score at 18 months than at baseline" (i.e., reduced information needs over the study period) as the response variable. Three variables from a preliminary univariate analysis were entered into the final multivariate regression model (Table 3). Reduced information needs were associated with having a baseline total LINQ score above the study population mean of 11 points (i.e., great needs for information) and having established contact with a physiotherapist during the study period. Getting a specific, assigned GP during the study period had a close to significant association with reduced information needs. Other variables, such as patients' age, gender, lung function, medications, education level, and symptoms/health status (CAT/CCQ/mMRC), smoking status, and whether patients had had contacts with a COPD nurse were not associated with changes in information needs.

Both at baseline and 18 months, the patients expressed the greatest needs for information in the LINQ domains "Diet" and "Self-management," moderate needs for information about "Disease knowledge" and

“Exercise,” and the least needs for information about “Medicines” and “Smoking” (Figure 1). Only in domain “Disease knowledge” the change in the mean domain score over time was significant (percent of maximum domain scores: 36% to 51% [ $P<0.001$ ]), which indicated an increased need for information about disease knowledge in the study population. However, we could not find any significant associations between the changes in the LINQ domain “Disease knowledge” and other clinically significant variables.

### **Analysis of the subgroups: Four levels of information needs**

Although the mean LINQ scores for the study population as a whole remained stable over the study period, 43.3% of the patients reported reduced information needs, and 56.7% reported increased or stable information needs. To present this result more clearly, we divided the patients into four approximately equal-sized groups by baseline LINQ scores (Figure 2). The first group (Figure 2: a) had the lowest information needs (1-7 points, 19.8% of the patients), the second group (Figure 2: b) had medium low information needs (8-10 points, 32.8%), the third group (Figure 2: c) had medium high information needs (11-13 points, 22.2%), and the fourth group (Figure 2: d) had the greatest information needs (14-25 points, 25.3%). We then illustrated the movements of patients from each baseline group to the groups at the 18-month follow-up.

Most patients remained in the same group they had been in at baseline. Patients in the group with the *lowest* information needs throughout the 18-month study period had tendencies to have lower lung function measures, more exacerbations at baseline, more inhaled medications, more often an assigned GPs, and more contacts with physiotherapists than the patients with highest information needs or who tended to move towards higher information needs over the study period.

## **Discussion**

### Main findings

In this study of 293 primary care patients with COPD in Sweden, we found that although the GPs at the healthcare centers had been given a COPD education at the baseline, a large proportion of the patients remained at the same level of information needs about COPD over the course of 18 months. However, many patients reported substantial changes in their levels of information needs. Reduced information needs were most clearly associated with onset of pulmonary rehabilitation during the 18-month study period. Subgroup analyses based on four levels of information needs showed that patients with stable COPD (no exacerbations during the study time) had also fewer care contacts and tended to have greater needs for information about COPD than those with more severe or unstable COPD. Conversely, patients with less stable COPD that required more treatment had more care contacts and lower LINQ scores, indicating low needs for further information about COPD. These findings do not prove causality, but suggest the possibility that patients who have not recently received active COPD care with educational elements (e.g. due to an intermittently stable phase of the disease) may forget the learnings from earlier patient educations and thus develop new or increased needs for information and support.

## *The role of patient education in meeting patients' information needs*

Patient education is central to increasing COPD patients' self-management skills, improving quality of life, and helping patients quit smoking, which makes it crucial to improving prognosis (8, 23, 24). As COPD patients frequently feel stigmatized (25), and time-pressured GPs often deprioritize COPD management (26), educating patients about COPD is often relegated to second place. In fact, it is most often started when patients' lung function has declined below 50% of predicted (i.e., GOLD stage 3) and they have experienced repeated exacerbations, hospital admissions, significant everyday symptoms, and reductions in health-related quality of life (27, 28).

There is strong evidence of positive associations between patient education and changes in clinical outcomes (10, 16). Our finding about the positive impact of pulmonary rehabilitation on patients' information needs did thus not come as a surprise. In line with our findings, the U.K. research group that developed the LINQ found an association between patient education via pulmonary rehabilitation and reduced information needs (the LINQ scores) (16). A 2020 study from Spain observed patients' post-educational LINQ scores similar to those found by the U.K. group (29). The patterns of information needs found in both of those studies were similar to the patterns in our study population. Unlike our study, however, neither of the previous studies observed associations between patient's current status of COPD and perceived needs for information. Additionally, the participants in our study had higher mean total LINQ scores (i.e., had greater information needs) both at baseline and follow-up than the participants in the U.K. study or the Spanish study (no pre-interventional assessment in the latter study). This was probably because the target group of the educational intervention in our study (PRIMAIR) was GPs rather than patients, which made it likely that the effects on patient outcomes would be relatively modest (30). In our study population, women had smoked more, had a lower level of education, and had more anxiety/depression than men. Despite this, unlike a previous Japanese study, we did not find positive associations between women and high information needs (31). Previous research has reported positive patient effects of having an assigned GP and a contact with a COPD nurse in Swedish primary care (8, 14). In the current study, having an assigned GP seemed to play a role in reducing patients' current information needs, whereas such associations were not found regarding contacts with COPD nurses.

## *Strengths and limitations*

The exploratory subgroup analyses were a strength of the study, as they allowed us to identify important tendencies that would have been overlooked if we had only studied the population as a whole. A limitation of studying subgroups, however, is that the results may be less generalizable because of decreasing sample sizes and statistical power. Moreover, multiple comparisons that are performed in small sample sizes bear the risk of false-positives. Because of this limitation, we chose to describe the tendencies rather than exact numeral values as the results of the performed analyses of the subgroups.

Although the two types of educational interventions that were compared in PRIMAIR (traditional lecturers vs. case method learning) were not associated with LINQ scores at the end, there is a possibility that the two educational methods still may have confounded the results of the current study. However, as we

previously have not been able to show that any one of the given educations was superior the other (12, 18) we assess the risk for confounding as small.

In clinical use, the brevity of the LINQ is a strength. A Canadian research group evaluated the feasibility of the LINQ and found it useful even in brief consultations (32). However, using the LINQ led to some limitations in the current study. For example, a power calculation based on previous publications about LINQ scores (rather than CCQ scores as in PRIMAIR) would have been preferable when designing the current study. However, this was not possible, as only an informal minimal clinically important difference (MCID) is currently available for the LINQ (16). A related difficulty was defining “high” and “low” LINQ scores; we pragmatically chose to make this distinction at the mean value of the total LINQ score in the study population.

The self-reported data from a real-world setting that our questionnaire provided were valuable because they gave us first-hand, up-to-date information about symptoms, medications, and perceived health status. However, self-reported data can be biased, as patients can differ in understanding and remembering. Moreover, patients’ information-seeking behavior may have affected their intuitive responses to the LINQ. This behavior is normally affected by several dimensions: cognitive (i.e., a subjective need to bridge a gap in knowledge), affective (e.g., emotions like desire for attention, doubt, or likes/dislikes), and situational (e.g., access to information sources or the complexity of the patients’ medical situation, for example, due to multimorbidity) (33). Although validated, the LINQ is still a relatively unknown and unstudied clinical tool, and our study contributes to new information about its usability in clinical practice. To further improve the usability of the LINQ, researchers should consider validating a categorization of levels of information needs or a cut-off between high and low levels of information needs. The MCID of the total LINQ score and domain scores should also be formally validated.

## Conclusions

In summary, COPD patients’ perceived information needs are not constant over time. Changes in information needs are determined by the patients’ current clinical stage. Patients in a stable phase of COPD tend to develop greater information needs over time. Attention should thus be paid both to starting patient education early and to vigilantly offering patient education and continual support throughout the life-long course of COPD, rather than only offering it when the patient’s health has deteriorated or is at obvious risk.

## Abbreviations

CAT = The COPD Assessment Test

COPD = Chronic obstructive lung disease

GOLD = The Global Initiative for Chronic Lung Disease

GP = General practitioner

LINQ = The Lung Information Needs Questionnaire

MCID = Minimal clinically important difference

mMRC = The modified Medical Research Council dyspnea scale

PHCC = Primary healthcare center

PRIMAIR = The PRIMAIR study

STROBE = Strengthening the Reporting of Observational Studies in Epidemiology agreement

## Declarations

### **Ethics approval and consent to participate**

Prior to patient enrollment, all PHCC managers, GPs, and patients provided written informed consent to participate in the study. The study was approved by the Regional Ethical Review Board of Stockholm (ref 2013/232-31/5). Written informed consent was obtained from the participants following the WMA Declaration of Helsinki Ethics principles for medical research involving human subjects. The study was registered at [www.clinicaltrials.gov](http://www.clinicaltrials.gov) on 10 August 2014, Identifier NCT02213809. The first participant was enrolled on 14 August 2014.

### **Consent for publication**

Not applicable.

### **Availability of data and materials**

The datasets generated or analyzed during the current study are not publicly available because the data sets contain confidential information. Thus, due to ethics restrictions concerning the data sets, they are available from the corresponding author upon reasonable request.

### **Competing interests**

HS has received honoraria for educational activities from Boehringer Ingelheim, Novartis, AstraZeneca, Chiesi, and TEVA, an unrestricted research grant from AstraZeneca, and has served on advisory boards arranged by AstraZeneca, Novartis, Chiesi, and GlaxoSmithKline. AN has received compensation for educational activities from AstraZeneca and SM from Novartis. BS has received honoraria for educational activities and lectures from AstraZeneca, Boehringer Ingelheim, Chiesi, Meda, Novartis, and TEVA and has served on advisory boards arranged by AstraZeneca, Novartis, Meda, TEVA, GlaxoSmithKline, and Boehringer Ingelheim. IK reports no competing interests.

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### **Authors' contributions**

HS, IK, SM, BS, and AN conceived and designed the study. HS collected the data. HS, BS, and AN analyzed the data. HS wrote the paper. All authors edited, revised, and approved the final manuscript.

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## Tables

Table 1. Patient characteristics at baseline (n=293).

<b>Characteristics</b>	<b>All patients n=293</b>
<b>Age</b>	
Years, mean (95% CI)	71.1 (70.1-72.0)
Age distribution, n (%)	
Age 35-64 years	54 (18.4)
Age 65-79 years	186 (63.5)
Age 80-93 years	53 (18.1)
<b>Gender</b>	
Female, n (%)	166 (56.7)
Male, n (%)	127 (43.3)
<b>Education</b>	
>9 years, n (%)	125 (44.5) (Missing data=12)
<b>Smoking intensity</b>	
Pack years <sup>1</sup> , mean (95% CI)	34.4 (31.8-36.7) (Missing data=27)
<b>Lung function</b>	
FEV1 <sup>2</sup> % of predicted value, after bronchodilator, mean (95% CI)	56.4 (54.8-57.9)
GOLD 2 <sup>3</sup> , n (%)	203 (69.3)
GOLD 3 <sup>3</sup> , n (%)	90 (30.7)

CI, confidence interval; OR, odds ratio.

<sup>1</sup> Number of pack years = (number of cigarettes smoked per day × number of years smoked)/20.

<sup>2</sup> Forced expiratory volume of one second.

<sup>3</sup> COPD severity grade according to the Global Initiative for Chronic Obstructive Lung Disease (GOLD) 2013: GOLD 2 (moderate, 50% ≤ FEV1 < 80% of predicted), GOLD 3 (severe, 30% ≤ FEV1 < 50% of predicted).

Table 2. Changes in patients' smoking intensity, exacerbations, body mass index, comorbidities, health status, medication, and care provider contacts over the 18-month study period.

Characteristics	All patients n=293		P value
	Baseline	18 months	
<b>Smoking</b>			
Current smoker, n (%)	88 (30.0)	79 (27.0)	n.s.
<b>Exacerbations<sup>2</sup></b>			
Acute exacerbation in the last 6 months, n (%)	100 (34.1)	94 (32.6)	n.s.
<b>Body Mass Index</b>			
Kg/m <sup>2</sup> (95% CI)	25.9 (25.3-26.6) (Missing data=12)	26.0 (24.9-27.1) (Missing data=15)	n.s.
<b>Comorbidities</b>			
Hypertension, n (%)	149 (50.9)	152 (51.9)	n.s.
Asthma, n (%)	55 (18.8)	59 (20.2)	n.s.
GERD <sup>3</sup> , n (%)	67 (22.9)	59 (20.2)	n.s.
Heart disease, n (%)	62 (21.2)	63 (21.5)	n.s.
Anxiety/depression, n (%)	51 (17.4)	48 (16.4)	n.s.
Type 2 diabetes, n (%)	38 (13.0)	41 (14.0)	n.s.
Chronic pain, n (%)	34 (11.6)	38 (13.0)	n.s.
No comorbidity, n (%)	52 (17.7)	45 (15.4)	n.s.
<b>Health status<sup>4</sup></b>			
CAT, total score of 0-40, mean (95% CI)	15.8 (14.9-16.7) (Missing data=9)	16.6 (15.7-17.6) (Missing data=23)	<0.05
CCQ, mean score of 0-6, mean (95% CI)	1.93 (1.80-2.06) (Missing data=1)	2.03 (1.89-2.16) (Missing data=7)	<0.05
mMRC dyspnea score $\geq$ 2 points, n (%)	125 (43.1) (Missing data=3)	149 (51.6) (Missing data=4)	<0.05
<b>Medication<sup>5</sup></b>			
No regular inhaled medication, n (%)	24 (8.2)	23 (7.9) (Missing data=1)	n.s.
ICS only, n (%)	11 (3.8)	7 (2.4) (Missing data=1)	n.s.
LAMA and/or LABA only, n (%)	85 (29.0)	75 (26.3)	n.s.

		(Missing data=8)	
ICS+LAMA only, or ICS+LABA only, n (%)	54 (18.4)	87 (30.6) (Missing data=9)	<0.01
ICS+LABA+LAMA only, n (%)	119 (40.6)	103 (36.3) (Missing data=9)	n.s.
<b>Care professional contacts, past 6 months</b>			
Has an assigned general practitioner, n (%)	217 (75.6) (Missing data=6)	188 (65.3) (Missing data=5)	<0.01
Has contact with a COPD nurse, n (%)	115 (39.2)	118 (41.1) (Missing data=6)	n.s.
Has contact with a physiotherapist, n (%)	35 (11.9)	51 (17.7) (Missing data=5)	<0.05
Has contact with a nutritionist, n (%)	22 (7.5)	24 (8.3) (Missing data=5)	n.s.

CI, confidence interval; OR, odds ratio.

<sup>1</sup> Number of pack years = (number of cigarettes smoked per day × number of years smoked)/20.

<sup>2</sup> COPD exacerbation defined as a patient-reported intermittent period of deterioration in the disease in the previous six months that had warranted an unscheduled or emergency visit to a PHCC or hospital and/or additional medication with antibiotics and/or oral steroids.

<sup>3</sup> Gastroesophageal reflux disease.

<sup>4</sup> The COPD Assessment Test (CAT), score 0-40; the Clinical COPD Questionnaire (CCQ), score 0-6, the mean of the minimum of 8 items of 10; the Modified Medical Research Council Dyspnea (MRC) scale, score 0-4.

<sup>5</sup> LABA = long acting beta agonist, LAMA = long acting muscarine agonist, ICS = inhaled corticosteroid

Table 3. Patient-related factors associated with reduced perceived needs for information<sup>1</sup> over the study period, measured at follow-up (18 months).

Factor	Unadjusted OR <sup>2</sup>	95% CI for unadjusted OR	P value	Adjusted OR <sup>3</sup>	95% CI for adjusted OR	P value
High level of information needs at baseline <sup>4</sup>	3.09	1.91-4.99	<0.001	3.17	1.93-5.23	<0.001
Pulmonary rehabilitation started during study period	2.22	1.08-4.57	0.030	2.26	1.05-4.86	0.038
Got assigned a GP (responsible for care) during study period	2.96	1.21-7.08	0.017	2.37	0.92-6.11	0.075

CI: confidence interval; OR: odds ratio.

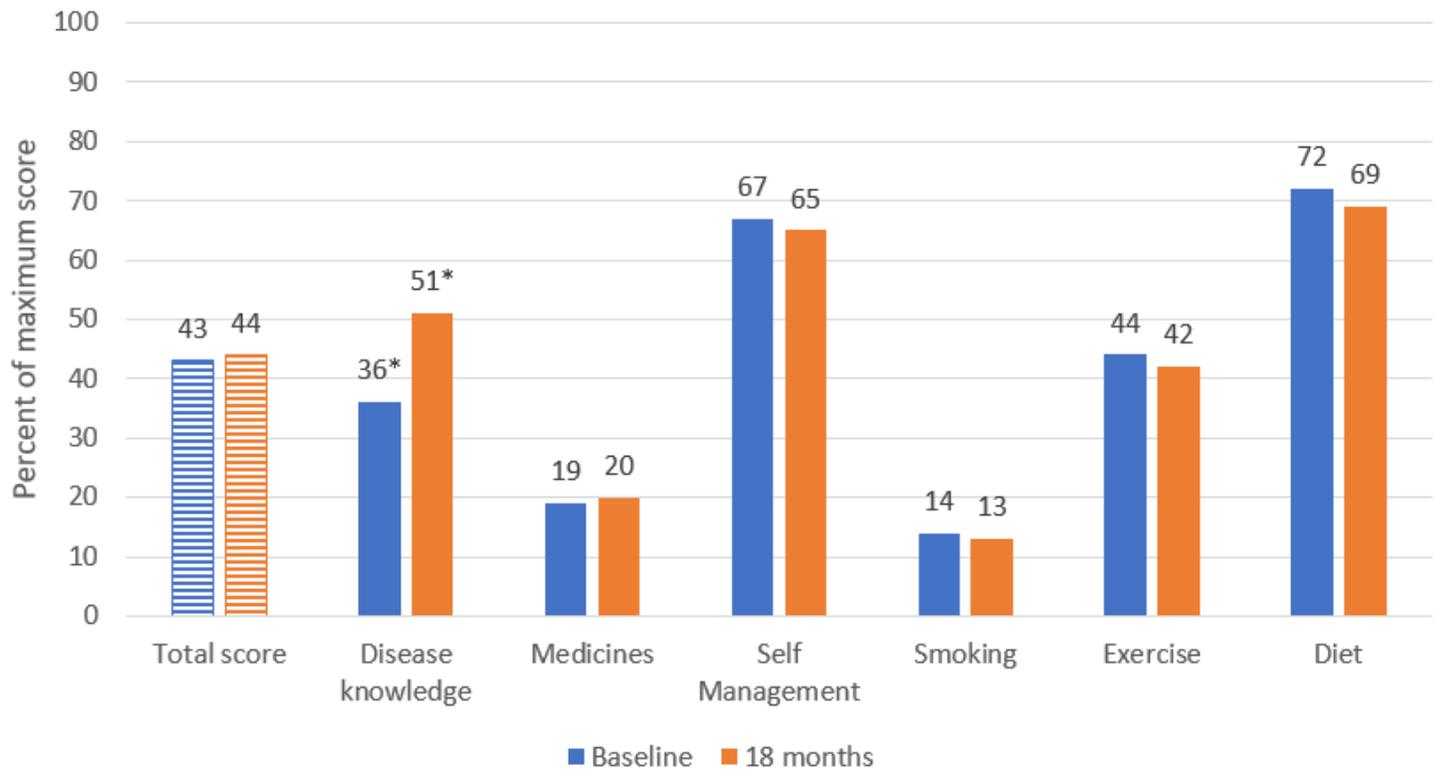
<sup>1</sup> Measured as changes in the Lung Information Needs Questionnaire (LINQ) total score between baseline and 18 months.

<sup>2</sup> Unadjusted logic regression analysis.

<sup>3</sup> Logistic regression analysis with all factors adjusted for each other.

<sup>4</sup> Total LINQ score  $\geq 11$  (11 = mean score in the study population).

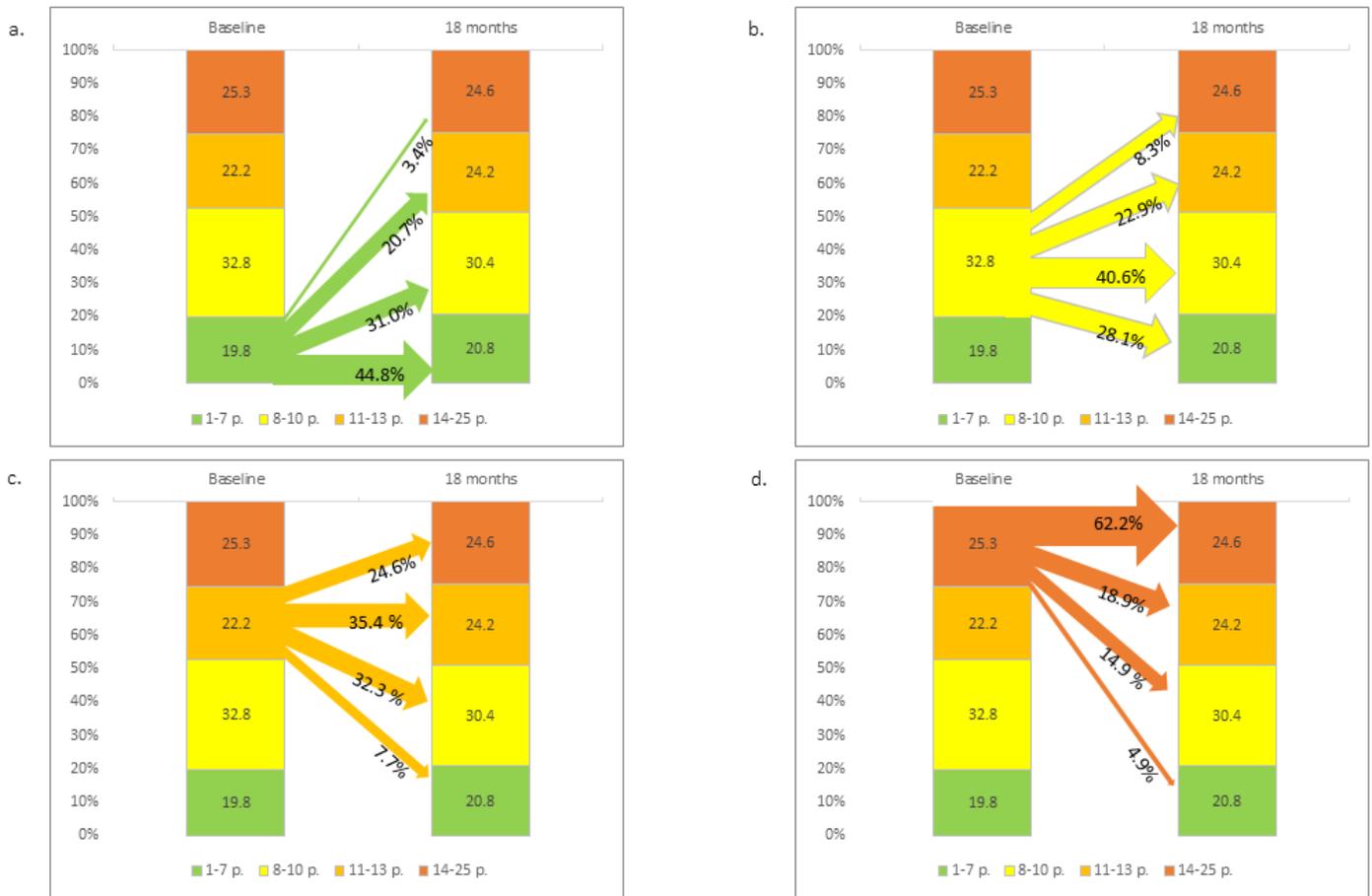
## Figures



**Figure 1**

Changes from baseline to 18 months in the total scores of The Lung Information Needs Questionnaire (LINQ), mean total score and mean score for each domain presented as percentage of maximum scores.

\* 36% vs. 51%,  $P < 0.001$



**Figure 2**

Changes in patients' perceived information needs between baseline and the 18-month follow-up according to Lung Information Needs Questionnaire (LINQ) scores. Patients were divided into four approximately equal-sized groups (a-d) by baseline LINQ scores. Points: p.