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# The Lung Information Needs Questionnaire: Development, preliminary validation and findings

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**Summary**
*Study objectives:* Many chronic obstructive pulmonary disease (COPD) patients are dissatisfied with the information they are given. A brief questionnaire completed prior to the clinical encounter would assist health professionals identify areas of information need.
*Design:* Ten focus groups of 59 patients assisted in the process of questionnaire construction. Three hundred and four patients (return rate 63%) responded to a postal questionnaire.
*Results:* Twenty-one per cent did not know the name of their disease, 3% reported medication non-compliance and 8% were confused with medicines. Fifty-five per cent of patients were exercising inappropriately, 8% did not know what to do when breathing worsened and 36% did not know when to call an ambulance. All six of the Lung Information Needs Questionnaire domains discriminated significantly as a function of health professional contact. Retest reliability for the six domains varied between .66 and .98, and for the total score was .89. $\alpha$ was .62.
*Conclusions:* Patients can act as experts during the process of questionnaire construction. Information needs vary between patients but tend to be high for non-drug related aspects of self-management COPD. This questionnaire can be used to guide the clinical encounter.

## Introduction

Education is central to the management of chronic obstructive pulmonary disease (COPD)[1,2] and is a core component of pulmonary rehabilitation.[3] It is therefore of concern that many COPD patients

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*Abbreviations:* COPD, chronic obstructive pulmonary disease; LINQ, Lung Information Needs Questionnaire

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report dissatisfaction with the information provided,[4] though such dissatisfaction is widespread in medicine and occurs for several reasons.[5] In time-constrained clinical situations, pre-interview questionnaires can be a useful method for alerting the clinicians to the educational needs of the patient.[6]

There are two ways of assessing patients' understanding of COPD: (a) knowledge and (b) information needs. There are several COPD patient knowledge assessments, based either on questionnaires (open or closed questions)[7–9] or using scenarios.[10]

Patient knowledge questionnaires are useful for assessing the effectiveness of educational programmes. Such questionnaires vary in both content and length reflecting variability in what clinicians believe COPD patients should know. The longer ones provide a more comprehensive form of assessment. For example, the Bristol COPD Knowledge Questionnaire (BCKQ) has 65 items and takes about 20 min to complete. Thus, comprehensiveness is achieved at the price convenience for everyday clinical use. Patients differ in terms of depth and type of information that they seek, particularly when the disease is life threatening—as in advanced COPD,[11] and so, whatever their length or content, such questionnaires can fail to reflect the patient perspective in terms of what the patient wants to know. What an individual patient wants to know is a reflection of the fact that psychological problems affect the way patients seek and respond to education.[10] Guidelines recommend that education should take into account the differing needs of patients at differing stages of their disease.[1]

An alternative strategy is to measure *information needs* which can be defined in two ways. First, if a patient expresses a desire for more information, then the patient has an information need—thereby taking into account differing levels of educational need. Second, if a clinician believes that a patient's response to a question indicates the patient's self-management is compromised, then this may also indicate that the patient has an information need. In contrast to knowledge questionnaires, clinician defined information needs provide a much limited focus, namely on areas where lack of knowledge can compromise the patient's ability to self-manage. Such evidence includes research that smoking cessation[12] and exercise[13] affect prognosis and quality of life, and that early response to symptoms reduces the impact of an exacerbation.[14,15]

An information needs questionnaire does not necessarily inform the clinician what the patient knows, but it does show that there is an aspect of education that needs attention, and because it is designed with brevity in mind is particularly suited for pre-interview assessment. Our aim was to construct an information needs questionnaire that would be convenient to use as a pre-interview assessment to guide the clinical encounter. Patients were involved throughout the development of the questionnaire to reflect the patient perspective and to avoid language styles familiar to health professionals but not to patients.[5]

## Methods

### Qualitative methods

The Lung Information Needs Questionnaire (LINQ) was developed using an iterative procedure which relied primarily on patient comment or patient data. Five audio-taped focus groups ($n = 29$ COPD patients) were carried out to establish information needs as perceived by patients. Participants were recruited from primary and intermediate care databases in Plymouth, UK. The inclusion criteria were, at least 40 years old, diagnosis of COPD made by a clinician based on clinical features and spirometry (performed in the prior 6 months) according to BTS criteria. Exclusion criteria were diagnosis of asthma; patients who had taken part in a pulmonary rehabilitation course, substantial co-existing morbidity, serious exacerbation in last 4 weeks or likely to become severely ill, unable to give informed consent or unsuitable for inclusion, and those patients involved in other research projects. For each focus group at least two mild or moderate COPD and two severe COPD patients using BTS criteria, and at least two females and two males were among the eight people originally invited.

The first version of the questionnaire was based on the information needs identified by patients using loose content analysis. The wording of the items and response options was examined in a further five focus groups ($n = 30$, total 59). Inclusion criteria were the same as for the first series except that we did not exclude patients who had attended rehabilitation or engaged in previous research. Patients first completed the questionnaire, and then the moderator asked them to discuss each item in turn, ensuring that there was consensus about the suggested changes before moving on to the next question. Patients' suggestions led to word changes to the questionnaire, which were then further discussed by the participants in subsequent groups leading to a gradual process of refinement of the questionnaire.

The same moderator (MEH), who had prior experience running COPD and asthma focus groups, was used for all 10 groups. The guide to moderation used in the initial five groups was based on the clinical knowledge of two of the authors (RCMJ and KEH), who had experience in developing and running pulmonary rehabilitation programmes.[4]

## Quantitative methods

Patients were recruited to complete questionnaires using a postal survey. Patients who were electronically coded for the diagnosis of COPD were recruited from three primary care practices. Practices 1 and 2 had a special interest in COPD whereas Practice 3 did not. In addition, a convenience sample of patients (with a diagnosis of COPD) was recruited from a database of patients who had attended pulmonary rehabilitation.

Participants were sent the LINQ (some being sent the long and some the final version, see later) by post and asked to return it in a freepost envelope. A subsample of patients who had returned their questionnaires were sent a second questionnaire after an interval of 14 days with a written explanation that we were testing the stability of the questionnaire. In addition to the LINQ items, patients were asked to provide the year of their birth and gender, and to indicate which health professionals they had contact with from the following list: (a) practice nurse/nurse practitioner; (b) respiratory specialist nurse; (c) respiratory specialist physiotherapist; (d) outpatient clinic/hospital consultant; (e) admission to hospital with breathing problems; (f) attended pulmonary rehabilitation programme.

## Analysis for quantitative methods

Five of the domain scores were calculated by summing the item scores in each domain (see Table 2) where $0 =$ no information need and 1–3 indicates a level of need. In the case of the smoking domain, all patients who were not smoking were given a domain score of 0 irrespective of their response to the remaining two smoking questions. Those currently smoking were given a domain score that was the sum of the three smoking questions. Retest reliability was calculated using Pearson correlations between the first and second presentation for each of the domain subscales. The remainder of the analysis was based on the common items between versions 8 and 9 for the first or only presentation. First, we provide a descriptive analysis of the frequency and percentage of responses to individual items. Second, we assessed the cross-sectional sensitivity of the scale to educational input by using $t$-tests to compare domain scale scores between those who had or had not attended pulmonary rehabilitation, been treated by a specialist nurse, been treated by a physiotherapist, attended an outpatient clinic, or had attended hospital for their lung disease. Cronbach's $\alpha$ was used to evaluate internal consistency of the scale.

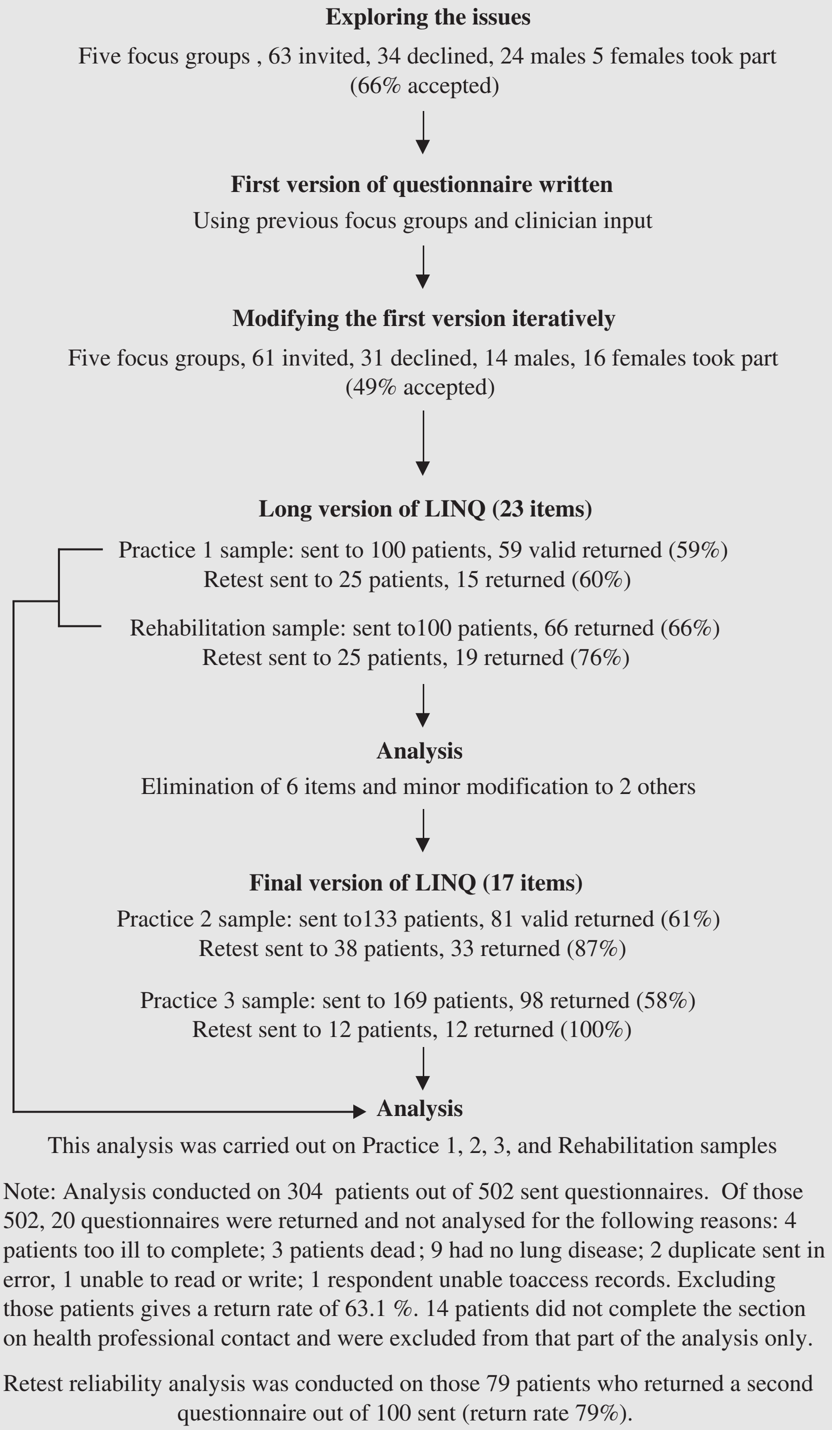
# Results

## Development of the questionnaire

The number and gender of patients in the two series of focus groups is shown in Table 1. An initial version of the questionnaire was developed from the first series of focus groups. When patients evaluated the questionnaire in the second series of focus groups, they made a number of suggestions about the wording. These suggestions included changes to the phrasing of the questions. For example, the researchers suggested a question about "exercise" but following discussion with patients it appeared that "exercise" often had a far more specific interpretation similar to sport, and excluded brisk walking. The suggested alternative wording was "physical activity". Patients also suggested changes to the response format. For example, whereas the researchers originally suggested a 'yes—don't know—no' option for several questions, in some cases patients pointed out that "you couldn't 'not know'". Many of the items in the final version are binary reflecting this patient perspective. In addition, patients commented on the importance of different types of information, and this was one factor in determining whether an item was included. For example, although not knowing the name of the disease may make no difference to a patient's self-management, it is distressing and so important to the patient. The changes in the questionnaire were iterative, and the patients showed considerable understanding of the subtleties of language usage from their particular perspective. Patients suggested minimal changes to the penultimate version to produce LINQ (long version).

LINQ (long version) was completed by 125 patients (see Table 1) and their responses analysed for the purpose of item reduction and item change, and this process was informed by freetext comments which were solicited from patients. Items were rejected if $>90\%$ of patients gave an identical response (thereby showing low discrimination). The

**Table 1** Development of LINQ.



**Exploring the issues**

Five focus groups , 63 invited, 34 declined, 24 males 5 females took part (66% accepted)

↓

**First version of questionnaire written**

Using previous focus groups and clinician input

↓

**Modifying the first version iteratively**

Five focus groups, 61 invited, 31 declined, 14 males, 16 females took part (49% accepted)

↓

**Long version of LINQ (23 items)**

Practice 1 sample: sent to 100 patients, 59 valid returned (59%)
Retest sent to 25 patients, 15 returned (60%)

Rehabilitation sample: sent to100 patients, 66 returned (66%)
Retest sent to 25 patients, 19 returned (76%)

↓

**Analysis**

Elimination of 6 items and minor modification to 2 others

↓

**Final version of LINQ (17 items)**

Practice 2 sample: sent to133 patients, 81 valid returned (61%)
Retest sent to 38 patients, 33 returned (87%)

Practice 3 sample: sent to 169 patients, 98 returned (58%)
Retest sent to 12 patients, 12 returned (100%)

↓

**Analysis**

This analysis was carried out on Practice 1, 2, 3, and Rehabilitation samples

Note: Analysis conducted on 304 patients out of 502 sent questionnaires. Of those 502, 20 questionnaires were returned and not analysed for the following reasons: 4 patients too ill to complete; 3 patients dead; 9 had no lung disease; 2 duplicate sent in error, 1 unable to read or write; 1 respondent unable toaccess records. Excluding those patients gives a return rate of 63.1 %. 14 patients did not complete the section on health professional contact and were excluded from that part of the analysis only.

Retest reliability analysis was conducted on those 79 patients who returned a second questionnaire out of 100 sent (return rate 79%).

only exception to this was item 7 (see Table 2) which was retained despite failing this test because of a common belief amongst clinicians that a proportion of COPD patients are non-compliant with medication. Items were also rejected if they were judged by the authors not to contribute additional useful clinical information, where this judgement was informed by informal written comment on the questionnaire. For example, the long version included items about the consequences of smoking, but these were rejected on the basis that the most important clinical

**Table 2** Frequency and percentage of responses to the items of the LINQ from 304 patients.

| Item no. | Wording of question | Domain code | Wording of answer | Frequency (number 304) | Percentage |
|---|---|---|---|---|---|
| 1 | What is the name of your lung disease? *Patient wrote a Freetext response for this item* | Disease knowledge 1 | Don't know (1) | 65 | 21.4 |
| | | | Any plausible lung disease however spelt (0) | 237 | 78.0 |
| | | | Missing | 2 | .7 |
| 2 | Has a doctor or nurse told you how this disease affects the working of your lungs? | Disease knowledge 2 | Yes (0) | 222 | 73.0 |
| | | | No (1) | 80 | 26.3 |
| | | | Missing | 2 | .7 |
| 3 | Has a doctor or nurse told you what is likely to happen in the future? | Disease knowledge 3 | Yes (0) | 125 | 41.1 |
| | | | No (1) | 172 | 56.6 |
| | | | Missing | 7 | 2.3 |
| 4 | Which of the following statements best describes what will happen to you over the next few years? | Disease knowledge 4 | Now that my disease is being treated, I will probably get better (1) | 13 | 4.3 |
| | | | Now that my disease is being treated, I will probably stay the same (1) | 104 | 34.2 |
| | | | I will get worse (0) | 98 | 32.2 |
| | | | I have no idea (1) | 87 | 28.6 |
| | | | Missing | 2 | .7 |
| 5 | Write the names of the inhalers or medicines you take for your lungs *Patient wrote a Freetext response for this item* | Medicines 1 | Name of medication (0) | 276 | 90.8 |
| | | | Some information given (1) | 18 | 5.9 |
| | | | Ticked the 'don't know' box (2) | 7 | 2.3 |
| | | | Missing | 3 | 1.0 |
| 6 | Has a doctor or nurse explained the reason for taking your inhalers or medicines? | Medicines 2 | Yes (0) | 273 | 89.8 |
| | | | No (1) | 25 | 8.2 |
| | | | Missing | 6 | 2.0 |
| 7 | Do you try to take your inhalers or medicines exactly as you have been instructed by your doctor or nurse? | Medicines 3 | Yes (0) | 287 | 94.4 |
| | | | No (1) | 10 | 3.3 |
| | | | Missing | 7 | 2.3 |
| 8 | Are you satisfied with the information doctors or nurses have given you about your inhalers or medicines | Medicines 4 | I understand everything I need to know (0) | 187 | 61.5 |
| | | | I understand what I have been told but would like to know more (1) | 87 | 28.6 |

Table 2 (*continued*)

| Item no. | Wording of question | Domain code | Wording of answer | Frequency (number 304) | Percentage |
|---|---|---|---|---|---|
| | | | I am slightly confused about my medicines (2) | 23 | 7.6 |
| | | | I am a very confused about my medicines (3) | 2 | .7 |
| | | | Missing | 5 | 1.6 |
| 9 | Which sentence best describes what you have been told to do if your breathing gets worse? (e.g., take two puffs instead of one) | Self-management 1 | I have been told what to do and the doctor/nurse has given me written instructions (0) | 37 | 12.2 |
| | | | I have been told but it isn't written on paper (1) | 194 | 63.8 |
| | | | I haven't been told but I know what to do (2) | 43 | 14.1 |
| | | | I haven't been told and I don't know what to do (3) | 24 | 7.9 |
| | | | Missing | 6 | 2.0 |
| 10* | Have you been told when to call an ambulance if your breathing worsens? | Self-management 2 | I have been told what to do and the doctor/nurse has given me written instructions (0) | 3 | 1.0 |
| | | | I have been told but it isn't written on paper (1) | 53 | 17.4 |
| | | | I haven't been told but I know what to do (2) | 127 | 41.8 |
| | | | I haven't been told and I don't know what to do (3) | 111 | 36.5 |
| | | | Missing | 10 | 3.3 |
| 11 | What best describes you? | Smoking 1 | Never smoked (go to Q 14) (0) | 38 | 12.5 |
| | | | Used to smoke but don't now (go to Q14) (0) | 217 | 71.4 |
| | | | Still smoking (go to Q 12) (1) | 44 | 14.5 |
| | | | Missing | 5 | 1.6 |
| 12 | Has a doctor or nurse advised you to stop smoking? | Smoking 2 | Yes (0) | 113 | 37.2 |
| | | | No (1) | 24 | 7.9 |
| | | | Question skip or missing | 167 | 54.9 |
| 13 | Has a doctor or nurse offered to help you give up smoking? (e.g., | Smoking 3 | Yes (0) | 59 | 19.9 |
| | | | No (1) | 67 | 22.0 |

| | | | | | |
|---|---|---|---|---|---|
| | give you nicotine gum, patches or referral to smoking cessation clinic) | | Question skip or missing | 178 | 58.6 |
| 14 | Have you been told by a doctor or nurse to try to do physical activity? (e.g., walking, brisk walking or other forms of exercise) | Exercise 1 | Yes (0) | 203 | 66.8 |
| | | | No (1) | 93 | 30.6 |
| | | | Missing | 8 | 2.6 |
| 15 Long version | Has a doctor or nurse told you how much physical activity (e.g., walking, brisk walking or other forms of exercise) you should do? | Exercise 2 | Yes (0) | 68 | 54.4 |
| | | | No (1) | 51 | 40.8 |
| | | | Missing | 6 | 4.8 |
| 15 Final version | Has a doctor or nurse told you how much physical activity (e.g., walking, brisk walking or other forms of exercise) you should do? | Exercise 2 | Yes and I know what to do (0) | 55 | 30.7 |
| | | | Yes and I am unsure what to do (1) | 8 | 4.5 |
| | | | Yes but I am unable to do it (1) | 40 | 22.3 |
| | | | No (2) | 71 | 39.7 |
| | | | Missing | 5 | 2.8 |
| 16 | How much physical activity (e.g., walking, brisk walking or other forms of exercise) do you do? | Exercise 3 | As little as possible (2) | 137 | 45.1 |
| | | | I make an effort (1) | 131 | 43.1 |
| | | | I push myself as much as I can (0) | 26 | 8.6 |
| | | | Missing | 10 | 3.3 |
| 17 | What have doctors or nurses told you about your diet or eating? | Diet 1 | Nothing (2) | 122 | 40.1 |
| | | | Lose or gain weight or Eat healthy food (1) | 116 | 38.2 |
| | | | Eat several small meals a day (e.g., 6 small meals instead of 3 large ones) (0) | 52 | 17.1 |
| | | | Missing | 14 | 4.6 |

The numbers shown in parentheses in the column headed 'wording of answer' gives the scores to be used when calculating domain scores.

*Wording of question changed between long and final version: the words 'if your breathing worsens' were added to the final version (as shown).

information is whether patients have been told to stop smoking and provided with help to do so and that it was unhelpful to ask questions that might induce feelings of guilt or blame about prior smoking history. In addition, clinical judgement and patient comment led to expansion of the response format of one item, and the inclusion of an additional word in another. The final version of LINQ differed from the long version in that six items were deleted, and there were minor changes to the wording of item 10 (see Table 2) and a change to the response format of item 15 (see Table 2) so as to provide additional clinical information.

## Quantitative results

### The sample

Data were obtained from 304 patients who had completed either the long or final version of the LINQ, with analysis restricted to only those items in the final version (see Table 1). There were 170 males and 128 females (six did not show gender), mean age was 70.2 years (SD = 9.7) with an age range of 39–91 years (three did not show age). The probability of attending pulmonary rehabilitation varied between the three practices. In the two practices with an interest in COPD, 19 out of 65 (29%) and 12 out of 54 (22%) had attended rehabilitation; whereas, in the COPD not-special interest practice, only two out of 70 (3%) had attended rehabilitation. As a validation check of the item asking patients if they had attended rehabilitation, we compared that question with those who had been recruited via the rehabilitation sample. Of the 59 responding, 55 (93.2%) indicated that they had attended rehabilitation (data were missing on 14 patients).

### Descriptive statistics

Table 2 shows the frequency and percentage of responses to each of the items of the questionnaire. Patients who did not smoke were instructed to skip the next two questions but in fact many of them completed these two questions. Therefore as a further analysis we cross-tabulated the smoking questions. Of those 44 patients who were still smoking, 41 (93.2%) reported that they had been told to stop, 28 (63.6%) had been offered help in smoking cessation.

### Reliability and stability and internal consistency

Retest reliability data were obtained from 79 patients, that being 79% of the total 100 patients sent a second questionnaire. The correlations were for the total score = .89, and for each of the six subscales: disease knowledge.77, medicines = .72, self-management = .66, smoking = .98, exercise = .78 and diet = .75. Cronbach's $\alpha$ for the total score was .62.

### Cross-sectional sensitivity of domain scores to health professional contact

We compared the scores of patients who had or did not have contact with a particular health professional. Patients had lower information needs on the disease knowledge domain if they had contact with a specialist respiratory nurse ($P = .000$), they had attended an outpatients clinic ($P = .001$), they had contact with a specialist respiratory physiotherapist ($P = .001$) and if they had attended rehabilitation ($P = .003$). Patients had lower information needs on the medicines domain if they had attended rehabilitation ($P = .018$), and they had lower information needs on self-management if they had been admitted to hospital with breathing problems ($P = .028$). Patients had lower needs on smoking if they had contact with a practice nurse ($P = .039$), if they had been admitted to hospital ($P = .048$) or if they had attended rehabilitation ($P = .010$). Patients had lower information needs for exercise if they had contact with a specialist respiratory physiotherapist ($P = .000$) or had attended rehabilitation ($P = .000$) and had lower information needs on diet if they had contact with a specialist respiratory physiotherapist ($P = .003$) or attended rehabilitation ($P = .000$).

## Discussion

We developed an information needs questionnaire using a methodology which depended to a large degree on patient input. The use of patients to help construct the wording of the questionnaire is designed to avoid language style differences that are known to occur between patients and health professionals.[5] We found that patients made helpful suggestions about the wording of the questionnaire, but that it is an iterative process—i.e., as the questionnaire improves, patients find additional ways of improving it. An important part of this process is to believe what patients say—e.g., to use a binary response format rather some other format which researchers believe is more sensitive to change and yet does not correspond to the patient's experience. Although the questionnaire reflects patient defined information need, it also covers knowledge which according to guidelines is central to COPD management: smoking cessation, exercise and self-management of exacerbations.[1,13]

The content of the LINQ can be contrasted with the currently most comprehensive COPD knowledge questionnaire, the BCKQ.[9] First, the LINQ is about a third of the length of BCKQ. Second, the content of LINQ is not just a subset of the BCKQ but asks different questions. For example, the BCKQ has detailed questions about the cause of COPD, including smoking, but does not ask whether the patient has been given help in stopping smoking. There are five questions in the BCKQ on exercise, but there is no assessment of whether the patient understands that they should push themselves as much as possible when exercising. Unlike the LINQ there is no assessment in the BCKQ about whether the patient knows when to call an ambulance. Thus, the difference in content between these scales shows that the methodology of focusing on information need rather than knowledge produces a different kind of scale.

The LINQ has good retest reliability for the total score and for all the subscales, and in addition, the scale is stable over time. We calculated the $\alpha$ coefficient, but there is no a priori reason for assuming that knowledge is consistent either between items within a domain or between domains. That we recorded a coefficient of .62 is probably due a tendency for patients to be well or badly managed across a range of information.

As an indicator of cross-sectional sensitivity, all six domains discriminated between different kinds of health professional contact, but different types of contact affected different domains, and no type of contact was associated with difference on all domains. Pulmonary rehabilitation was associated with less information needs on five out of the six domains, whereas contact with a practice nurse and contact with a specialist respiratory nurse was associated with less information needs on only one domain—but a different domain in either case. Our research has not yet demonstrated longitudinal sensitivity (i.e., responsiveness to change), but data are being collected.

In addition to providing reliability, stability and preliminary validation data, this study provides information about level of information needs in a sample of patients recruited from primary care and from those attending a pulmonary rehabilitation clinic. Information needs concerning medicines were generally low—e.g., only 8% reported being confused by their medicines. We also found that the majority of patients reported compliance with medication consistent with other recent research,[4,15] though this finding is different from that of an earlier study.[16] By contrast, information needs about non-drug related aspects of self-management were higher, and this is particularly relevant to the domains where self-management affects outcome, such as smoking cessation,[12] exercise[14] and correct self-management.[13] Forty-four patients (14% of the total sample) reported being current smokers, and of those 44, 36% reported that they had not been offered help with smoking cessation. Despite the importance of exercise, 30% of patients said they had not been told to exercise, and 40% had not been told how much exercise to do. Only 9% were exercising properly. Twenty-two per cent of patients had not been told what to do when their breathing got worse and 36% had not been told and did not know when to call an ambulance.

We cannot say to what extent patients have been given information and then forgotten it[5] but whatever the cause it appears from our data that patients' information needs have not been met. This particularly applies to non-drug related areas, and could have a serious impact on their self-management. Our data on reported compliance is consistent with other recent data[4,15] suggesting that compliance is good with medication, but the problem appears to be that many patients do not have the information to comply with non-drug aspects of self-management. There is no good reason for supposing this problem is isolated to the South West of England.

## Conclusions and comparison with knowledge questionnaires

This paper shows that questionnaire construction can be assisted by using patients as experts. The LINQ is available for use as a pre-interview assessment to identify topics that require educational input, in contrast to a knowledge questionnaire measuring the patient's knowledge where knowledge has been defined by the selection of topics by researchers. When used in an audit context, the LINQ will reflect patient satisfaction with the educational process rather than knowledge, and although the LINQ and knowledge questionnaires may both be useful for COPD audit, the LINQ is specifically designed to aid the clinical interview. The LINQ assesses areas that may be of concern to patients, but does not cover all areas that may require educational focus for a particular patient—e.g., information need about sexuality is not covered. The LINQ is restricted in this way as our objective was to have a short questionnaire which is easy to use in a clinical context. The LINQ can help guide the clinical interview, but is not a substitute for an effective therapeutic interaction by a clinician.

## Conflict of interest

This research was supported by an educational grant from Boehringer Ingelheim.

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*Ethics*: Ethical approval for all studies was given by the Plymouth Local Research Ethics Committee.

LINQ is available on www.linq.org.uk and can be copied without charge for clinical and not-for-profit research purposes.

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