

*The Patient: Patient-Centered Outcomes
Research*

**Chronic Obstructive Pulmonary Disease
Patients' Disease-Related Preferences**

A Study Using Conjoint Analysis

Giovanni Pisa, Siegfried Freytag, Rainer Schandry

Correspondence:

G. Pisa, Kantar Health, Landsberger Straße 284, 80687 Munich, Germany
e-mail: Giovanni.Pisa@kantarhealth.com

Electronic Supplementary Material 1

"Patient Preferences in COPD"

Main Questionnaire

73.22.123371.020

Hallo, my name is,and I am from Kantar Health, an independent medical market research company.

We contact you, because you are suffering from **Chronic Obstructive Pulmonary Disease** (or COPD).

Thank you very much that you agreed to participate in this interview.

In the first part of the interview we are looking for some background information about your COPD and want to understand the impact of this disease on your life. The second part mainly covers an exercise, which will help us understand your preferences with regard to different aspects of your COPD.

That is very important for pharmaceutical companies, who want to learn more about the needs of patients so that they can manufacture the products that exactly meet those needs.

The interview will take about 20 minutes to complete. We would like to reassure you that the information you provide will be treated in the strictest confidence. Your answers will not be attributable to you by name; they will remain completely anonymous. They will simply be added to that obtained from other physicians in order to give an overall picture of the situation in your country.

1. Background information about the patient's state of health, approx. 5 min

In the beginning we want to speak about your state of health.

As your doctor confirmed, you suffer from Chronic Obstructive Pulmonary Disease (COPD).

If you agree, for the purpose of this interview we will use the term COPD (Chronic Obstructive Pulmonary Disease) when we speak about your disease.

1. Please tell me which statement best describes how you have been feeling during the last 24 hours.

The CCQ Questionnaire

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CCQ contact information and permission to use: MAPI Research Trust, Lyon, France.

E-mail: PROinformation@mapi-trust.org – Internet: www.mapi-trust.org and www.ccq.nl

Van der Molen T, Willemse BW, Schokker S, Ten Hacken NH, Postma DS, Juniper EF. Development, validity and responsiveness of the Clinical COPD Questionnaire. Health Qual Life Outcomes, 2003 Apr 28;1(1):13

| CLINICAL COPD QUESTIONNAIRE | | | | | | | |
|--|--------------------|-----------------------|------------------|--------------------|--------------|--------------------|----------------------------------|
| Please circle the number of the response that best describes how you have been feeling during the past 24 hours. (Only one response for each question). | | | | | | | |
| On average, during the past 24 hours, how often did you feel: | never | hardly ever | a few times | several times | many times | a great many times | almost all the time |
| 1. Short of breath at rest? | 0 | 1 | 2 | 3 | 4 | 5 | 6 |
| 2. Short of breath doing physical activities? | 0 | 1 | 2 | 3 | 4 | 5 | 6 |
| 3. Concerned about getting a cold or your breathing getting worse? | 0 | 1 | 2 | 3 | 4 | 5 | 6 |
| 4. Depressed (down) because of your breathing problems? | 0 | 1 | 2 | 3 | 4 | 5 | 6 |
| In general, during the past 24 hours, how much of the time: | | | | | | | |
| 5. Did you cough? | 0 | 1 | 2 | 3 | 4 | 5 | 6 |
| 6. Did you produce phlegm? | 0 | 1 | 2 | 3 | 4 | 5 | 6 |
| On average, during the past 24 hours, how limited were you in these activities because of your breathing problems: | not limited at all | very slightly limited | slightly limited | moderately limited | very limited | extremely limited | totally limited /or unable to do |
| 7. Strenuous physical activities (such as climbing stairs, hurrying, doing sports)? | 0 | 1 | 2 | 3 | 4 | 5 | 6 |
| 8. Moderate physical activities (such as walking, housework, carrying things)? | 0 | 1 | 2 | 3 | 4 | 5 | 6 |
| 9. Daily activities at home (such as dressing, washing yourself)? | 0 | 1 | 2 | 3 | 4 | 5 | 6 |
| 10. Social activities (such as talking, being with children, visiting friends/ relatives)? | 0 | 1 | 2 | 3 | 4 | 5 | 6 |

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CCQ 24 hours - United Kingdom/English - Mapi Research Institute.
CCQ-24h_AU71_0_eng_GB101.doc

2. Please think of **the last 7 days**: How often did you use an emergency spray for your COPD?
_____ times in the last 7 days

3. Let's come back to your state of health: Please tell us with which of the following statements you agree most:

- When it comes to COPD I can hardly do anything myself to improve the state of my health
- When it comes to COPD I can very well do something actively to improve my state of health

4. Do you look for information about COPD (such as course of the disease, symptoms, medication)?

- No, I do not look for information
- Yes, I look for information

5. **INT: If yes in the previous question**

Which sources of information do you use most frequently?

- 1 Advocacy groups
- 2 Treating physician
- 3 Internet (e.g. search engine, Wikipedia)
- 4 Patient forums in the internet
- 5 Special information websites of pharmaceutical companies
- 6 Information brochures
- 7 Pharmacies
- 8 Personal contacts (e.g. other concerned persons within the circle of friends and acquaintances)

In the following questions we are focusing on the basic medication for your COPD.

6. Please think again of your basic medication (i.e. not your emergency spray) for the treatment of your COPD, that you take one or two times daily: through the improvement of which symptoms do you to conclude upon the onset of action of the medication?

Please do not mention more than 3 symptoms which allow you to conclude upon the onset of action of your medication.

7. And through which signs do you conclude that the effect of your COPD medication is decreasing?

Please do not enter more than 3 answers.

2. Conjoint-Exercise approximately 15 min


8. For the next 15 minutes, I want to do an exercise with you. Let's imagine the following situation:

Three patients suffering from COPD meet and talk about their disease. They talk about their current quality of life, their current medication and therapy goals. They discuss the following topics:

- dyspnea,
- performance capability (bodily resilience) due to COPD,
- sleep quality due to COPD,
- onset of action of the medication,
- frequency of administration of the medication,
- health state after awakening (day start) due to COPD,
- emotional state due to COPD base medication

In the following I will show you 15 sheets. Each sheet describes the current situation of the three persons A, B, and C. Their present situation is primarily influenced by the current treatment of their COPD. Please select the one person being in the best situation according to your opinion

 ***Please hand out the first of 15 self-completion sheets!***

 ***The respondent must select one patient (A, B or C), who in his opinion is in the best state of health.***

 ***Then hand out the remaining sheets, one by one!***

9. Please consider again your basic medication (i.e. not your emergency spray) for the treatment of your COPD: Which frequency of administration do you prefer?

- 1 Twice-daily (duration of action over 24 hours)
- 2 Once-daily (duration of action over 12 hours)

10. **INT: If code 1 in previous question, ask only item A, B, D!**

If code 2 in previous question, ask only item C, E!

Now please indicate to what extent you agree with the statements about your basic medication (i.e. not your emergency spray) for the treatment of your COPD:

| | | (1) Do not agree at all | (2) | (3) | (4) | (5) Fully agree |
|---|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| A | I prefer once-daily dosing, because I do not want to be reminded of my COPD too often | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| B | I prefer once-daily dosing, because I must not think of an additional second dose | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| C | I prefer twice-daily dosing, because with the second dose I feel safer over the night | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| D | I prefer once-daily dosing, because I expect that tolerability is better (less active substance in my body) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| E | I prefer twice-daily dosing, because I expect that tolerability is better (medication isn't very strong) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Thank you very much for your participation and the very interesting discussion.