
Clinical COPD Questionnaire

Background information and instructions for usage



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Information:

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Introduction: the Clinical COPD Questionnaire

The Clinical COPD Questionnaire (CCQ) has been developed to measure health status of COPD patients. The questionnaire consists of ten items, divided into three domains: symptoms, functional state and mental state. The CCQ is available in a week (7 day) version and a 24 hour version (this one can be used as a diary). Patients are asked to record their experiences during the last seven days (week version) or during the last 24 hours (24 hour version).

Qualitative methods were used for the development of the CCQ in order to make patients' opinions pivotal. During focus groups and in-depth interviews patients revealed complaints and limitations of their disease that they considered most important. These complaints and limitations were put before leading international (clinical) experts who selected the most important items, resulting in the final questionnaire.

The CCQ is valid, reliable and responsive to change in patients with COPD (including patients at risk for COPD).

A primary aim during development of the CCQ was to create a scale capable of measuring change in health status, for example, post intervention change. Research has shown that the CCQ can discriminate between groups of patients that differ in severity of the disease.

The procedure used to administer questionnaires can influence the results considerably. Therefore, it is of great importance to adhere to the instructions for usage in this document. *

Translations

The CCQ is available in 28 official translations performed by MAPI France. Please review website (<http://www.ccq.nl>) for available translations.

The Turkish translation of the CCQ is not translated by MAPI France, and is considered an unofficial translation, useful for clinical practice, but not for research purposes.

Directions for administration

General

The Clinical COPD Questionnaire (CCQ) is self explanatory and simple enough for most patients to complete on their own. The CCQ takes about two minutes to complete. The questionnaire utilises a seven-point scale where 0 = asymptomatic/no limitations and 6 = extremely symptomatic/totally limited.

If possible, the CCQ should be administered during a clinic visit and ideally before any discussion with a health professional (physician or study co-ordinator). If patients discuss their health state before completing the questionnaire, the response of the health professional to the patient's experiences may influence how the patient answers the questionnaire.

In most situations, the physician or the study co-ordinator will hand the questionnaire to the patient and ask that the completed questionnaire be returned to him. A small amount of time and support from the physician or study co-ordinator, such as advised below, will greatly enhance the quality of the data. However, patients should not receive advice about their answers or how interpret any question on the scale.

Use of the seven-point scale

To have complete confidence in the results of the CCQ, it is important that patients fully understand the seven-point scale. Explain, if necessary, that the numbers 1 through 6 represent all possible degrees of symptoms/limitations. Emphasise the direction: 0 represents the least limitation possible and 6 represents the greatest with 1, 2, 3, 4 and 5 representing the whole range of possibilities between.

Remind the patient that he is to choose only one answer per question.

Directions of recommendation

These are some directions we strongly recommend:

- Provide the patient with a quiet place in which to complete the questionnaire. Noisy waiting rooms and clinics are distracting.
- Patients should be on their own when they complete the questionnaire. Friends and relatives should wait in a separate room. You seek the patient's responses, not a family consensus!
- Patients have to complete all questions of the questionnaire by putting a cross or a circle around the most appropriate answer option.
- Tell the patient that all questions must be answered and that only one response may be given for each question.
- "Wrong" answers are not possible; the point is the own opinion of the patient.
- Remind the patient that they are scoring limitations experienced because of COPD and not because of any other problems.
- Remind the patient that these are limitations that have occurred in the last week (or last 24 hours).

- After the patient has completed the questionnaire the physician or study co-ordinator should check to ensure that all questions have been answered.
- We recommend printing the questionnaire on yellow paper. It has been demonstrated that this can positively influence the attention of responders during questionnaire completion.

Example

This is an example of how to fill in the questionnaire:

CLINICAL COPD QUESTIONNAIRE							
Please circle the number of the response that best describes how you have been feeling during the past week . (Only one response for each question).							
On average, during the past week , 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

Tips on dealing with problem situations

What if a patient seems unclear about the meaning of a question?
 Should you run into any problem of understanding, the best approach is to simply read out the question exactly as worded. You will probably find this effective. On hearing a question, most patients will provide an answer without the need for further clarification. If they do not, it may be appropriate to repeat the question again using the exact wording in the questionnaire. If the patient still says something like, "Well, what do you mean by?" the appropriate answer is, "Whatever it means to you". Under no circumstances should you reword the question in an attempt to explain it to the patient.

Scoring the Clinical COPD Questionnaire

General

The questions in the Clinical COPD Questionnaire (CCQ) are divided into three area's, or domains:

Symptoms: items 1, 2, 5 en 6
Functional state: items 7, 8, 9 en 10
Mental state: items 3 en 4

Individual items within the CCQ are equally weighted. The total score is calculated by adding the scores of the ten items and dividing that number by ten (= number of items). Additionally, it is possible to calculate the scores on each of the three domains separately. The total CCQ score, and the score on each of the three domains, varies between 0 (very good health status) to 6 (extremely poor health status).

Missing data rule

You should make large effort to prevent missing data! When data is missing or answers are ambiguous (e.g. double answers) the following rules have to be applied to calculate the CCQ scores.

Domain	No. items in domain	No. items required	% required items
Symptoms	4	3	75
Functional state	4	3	75
Mental state	2	2	100

When data is missing, the total CCQ score can still be calculated if the individual domains can be calculated. So when one question of the mental domain is missing, this domain score cannot be calculated, and so the total score cannot be calculated as well. When a patient fills in two answers on one question the data should be considered as missing.

When the three domain scores can be calculated, the total score is calculated by multiplying the domain score with the original amount of questions and adding these numbers and dividing by 10.

For example, when question 5 is not completed, or there are two answers, the scores will be calculating as follows:

For the symptom domain add the score from questions 1,2, and 6 and divide by 3. Calculate the other domain scores as usual.

To calculate the total score use the following algorithm: $((\text{symptom domain score}) \cdot 4 + (\text{functional state domain score}) \cdot 4 + (\text{mental state domain score}) \cdot 2) / 10 = \text{CCQ total score}$.

Minimal clinically important difference

It is important to be able to judge whether a particular change in score represents an important improvement or deterioration, or whether it represents a trivial change. We refer to the minimal amount of change that is important in the patient's day-to-day life as the "minimal clinically important difference" (MCID).

For the CCQ an average change in score of 0.4 for the total score has been shown to be the MCID.

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