# Measuring quality of life in COPD patients: Comparing disease-specific supplements to the EQ-5D-5L


## Abstract

### Objectives

Patients with chronic obstructive pulmonary disease (COPD) show impairments in health-related quality of life (HRQL). We aimed to find a disease-specific questionnaire for routine application in large cohorts and to assess its additional explanatory power to generic HRQL (EQ-5D-5L).

### Methods

1,350 participants of the disease management program COPD received the EQ-5D-5L combined with one of the three disease-specific tools: COPD Assessment Test (CAT), Clinical COPD Questionnaire (CCQ) or St. George's Respiratory Disease Questionnaire (SGRQ) (450 participants each). We compared metric properties and evaluated the Germany-specific experience based values (EBVS) and utilities in comparison to the Visual Analogue Scale (VAS). We calculated the additional explanatory power of the identified disease-specific tool on VAS through regression analysis.

### Results

344 patients returned the questionnaire. CAT, CCQ and SGRQ- group did not differ regarding baseline characteristics. The questionnaire specific response rates were 33.7% for CAT, 30.5% for CCQ and 34.6% SGRQ, thereof 94.0%, 94.3% and 65.6% valid answers, respectively.

EBVS was better suited to reflect VAS than utilities. CAT –increased the explanatory power by 10 percent.

### Conclusion

CAT outperformed CCQ and SGRQ and it increased the explanatory power of VAS. EBV combined with CAT seem superior to only generic or disease-specific approaches.



**Keywords:** CAT, CCQ, COPD, EQ-5D-5L, health-related quality of life, SGRQ

## 1.0 Background

Chronic Obstructive Pulmonary Disease (COPD) is characterized by persistent respiratory symptoms like cough, dyspnea, and airflow limitations. Moreover, COPD patients are prone to exacerbations, further worsening their situation [1]. Additionally COPD is the third leading cause of death according to the WHO [2]. The high public health relevance of COPD is not only substantiated by its epidemiological dimensions but also by the substantial detrimental effect of COPD on the health-related quality of life (HRQL) of affected people [3,4]. Referring to this crucial patient-relevant outcome, several HRQL-questionnaires with similar methodological qualities and psychometric properties have been applied in COPD patients [5]. HRQL questionnaires are usually classified as either generic, focusing on general aspects of life or disease-specific, focusing more on symptoms and clinical parameters. The advantage of a generic questionnaire is the easier comparison across different diseases, while disease-specific questionnaires cover a broader range on important aspects unique to the disease. One of the most established generic HRQL questionnaire is the EQ-5D-5L from the EuroQol group, the improved version of the long established EQ-5D-3L [6]. There are currently two value sets for Germany for the 5L version available, the experience based value set (EBVS) from Leidl et al.[7] and the utilities from Ludwig et al.[8]. The two value sets are based on different valuation approaches for the health states, allowing to answer different research questions. The utilities reflect average population preferences between hypothesized health states. This approach is used for calculation of quality-adjusted life years (QALY)[9], which is a common decision tool in health care resource allocation in the UK[10] and in some other countries while it is not politically accepted in Germany. The EBVS uses the patients' own evaluation of experienced health states, thus emphasizing the patient perspective on this endpoint. Provided, that valuations are adequately predicted at the group level, EBVS may reduce heterogeneity in individual valuation[7]. To the best of our knowledge, the experience-based and the utility-based value sets of the EQ-5D-5L have not been used in the German COPD population so far. In this target population, the use of the EQ-5D-5L

is very straightforward, its application is favorable in a clinical setting. Nevertheless, there are some concerns, that a generic HRQL questionnaire might not capture every disease-specific detail, especially in patients severely diseased [11,12]. Therefore, the combination of disease-specific and generic measures could be beneficial [13] in order to enhance the informative value of HRQL measures for decisions on pro-active patient management.

To improve healthcare and thereby HRQL, the German government introduced a disease management program (DMP) for COPD in 2005 to enhance care of COPD patients according to the existing guidelines. Participants reflect a well-documented and supervised group with confirmed COPD diagnosis providing a good target to measure interventions according COPD management and evaluate the DMP program over time. With the use of HRQL questionnaires as the outcome variables, we could evaluate this program and provide important information about the patients' perceived health.

This cross sectional study aims to

a) compare different properties of different COPD-specific questionnaires;

b) investigate the relationship between disease-specific quality of life and generic HRQL measures described by different value sets (EBVS versus utilities)

c) assess the additional explanatory value of the most favorable disease-specific questionnaire to the Visual Analogue Scale (VAS) of the EQ-5D.

## 2.0 Methods

The Ethics Committee of the Ludwig Maximilians University Munich approved the study (reference number 17-358). The project is founded by the Federal Joint Committee (G-BA), Innovation Fund, (funding code 01VSF16025).

### 2.1 Setting

Out of 49.686 members of AOK Bavaria statutory health insurance fund, who were enrolled in the DMP COPD before 31 December 2017, we randomly selected 1,350 participants.

For this subsample, we analyzed patient-level information from DMP documentation and health insurance claims data. Claims data was available for at least one-year prior DMP inclusion and date back to 2009 or to time of AOK enrollment (if not earlier than 2009). Self-reported HRQL questionnaires refer to current health states, or evaluate health states during the week prior survey.

### 2.2 Health-related quality of life questionnaires

EuroQoL Five-Dimensional Five-Level Questionnaire (EQ-5D-5L) [14] was used as the reference tool to assess generic HRQL in every participant. Additionally, we applied three different disease-specific HRQL questionnaires evenly distributed around the randomly selected 1350 participants. 450 participants (Group CAT) received the COPD Assessment Test (CAT), 450 (Group CCQ) the Clinical COPD Questionnaire (CCQ) and 450 (Group SGRQ) the St. George's Respiratory Disease Questionnaire for COPD patients (SGRQ-C) by mail.

Moreover, every participant received the Modified British Medical Research Council Dyspnea scale (mMRC) and a short list of demographical questions (educational degree, occupational degree, marital status, individuals living in the household). Exacerbation history and time for filling-out the questionnaire were assessed as well. Table 1 in the online supplement summarizes the characteristics of the different HRQL questionnaires, detailed descriptions are in the sections below.

#### 2.2.1 EQ-5D-5L

EQ-5D-5L questionnaire to patients consists of two parts, a descriptive system and a visual analogue scale (VAS). The first part entails five question giving information about five domains of life (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression) on a five-item Likert-scale. The second part (VAS) assesses the currently experienced health of the participants on a vertical thermometer between 0 and 100; the latter indicates best health state imaginable. Health states derived from part 1 were once valued by the Germany-specific experience-based values [7] and once

by the Germany-specific utilities [8]. By both value sets higher values indicate better health with an actual range between 0.920 and 0.104 (EBVS) or 1.000 and -0.661 (Utility), respectively.

**2.2.2 CAT**

The CAT is a short eight items questionnaire with six answer possibilities each to measure the impact of COPD on the health of the participants. Total score ranges between zero and 40, with higher values indicating worse health [15].Scores are calculated as the sum of the answers, with an allowed of maximal two missing items, where the average score of the remaining items has to be inserted.

**2.2.3 CCQ**

The CCQ measures COPD-specific HRQL within three domains (symptoms, functional state, and mental state), through ten questions with seven answer possibilities. Zero represents the best score and six the worst [16]. The number of allowed missing values differ in the different domains[17].

**2.2.4 SGRQ**

The SGRQ-C is a shorter version of the SGRQ especially developed for COPD patients[18]. It contains 40 questions, divided in two parts (Part I Symptoms score; Part II Activity and Impact scores) with three different scores for the three different components and a total score. Scores range from zero to 100, with 100 indicating the worst health state. The scoring algorithm uses different weights for different questions and is described detailed in the instruction manual, alongside with the handling of missing values[18].

**2.3 Reflection of COPD severity**

We calculated forced expiratory volume-one second % predicted (FEV1 % pred) using the GLI reference values according to age, sex, height and ethnicity [19] with the most recent FEV1 single measurement values in liter provided in the DMP documentation before the patients filled out the

129 questionnaire. According to these results based on the guidelines from the Global Initiative for
130 Chronic Obstructive Lung Disease (GOLD) participants were grouped in four groups according their
131 GOLD stages [20]. Because of the low number of participants with stages III and IV we combined
132 these groups. For better comparability, we combined the less severe groups as well. Furthermore,
133 we measured the mMRC, which is to evaluate dyspnea patients with respiratory disease. This self-
134 reported scale ranges between one and five; five corresponding to severe breathlessness[21].
135
136 **2.4 Statistical analysis**
137 First, we analyzed the study population regarding demographical, clinical and HRQL aspects in a
138 descriptive way. Potential differences between the three groups (CAT, CCQ, SGRQ) were evaluated
139 via $Chi^2$-test for categorical and via Kruskal-Wallis test for continuous variables. Moreover, we
140 compared the whole study population regarding demographic and clinical characteristics with the
141 group of non-responders.
142 Next, we assessed the correlations between the HRQL measures applied and disease-severity (GOLD-
143 stage) by Spearman's rank coefficient. We considered correlations <0.3 as weak, those ≥0.3 and <0.7
144 as moderate and those ≥0.7 as strong [22]. Subsequently, we assessed floor and ceiling effects of the
145 HRQL measures; defined as more than 15% of the participants reaching the best/worst HRQL
146 score[23]. Furthermore, we obtained correlations between VAS, EBVS and tariff-based values with
147 the respective disease-specific HRQL scores.
148 To support decision-making, the three questionnaires were also contrasted regarding their suitability
149 for routine application, which was reflected by response rate, number of evaluable answers and
150 time for completion. According to the results regarding applicability, we selected the most suitable
151 disease-specific measure for this study population.
152 Finally, we measured the additional explanatory power (R-squared) of the selected disease-specific
153 HRQL measure on VAS based on two linear regression models. The first model included the five EQ-
154 5D domains, the second included additionally the disease-specific HRQL score. Given that our study

primarily focuses on patient relevant benefits, using patient-reported VAS as point of reference seems justified.

All analyses were performed with the Software SAS (SAS Institute Inc., Cary, NC, USA, version 9.4) and we considered *p*-values of 0.05 or less statistically significant.

## 3.0 Results

### 3.1 Baseline characteristics

Mean age among the 344 participants was 68.5 years (Standard deviation 10.4), 60.6% of them were male and they were on average for 6.0 years enrolled in the DMP COPD program. Most of them had GOLD stage II (41.2 %) followed by stage I, III and IV with 31.3%, 22.0% and 5.4% respectively. Further results are shown in Table 1 stratified into three groups (CAT, CCQ, SGRQ) according to their received and answered questionnaire. Out of the 344 participants, 1.1% (n=4) only answered the generic HRQL but not their respective diseases specific questionnaire. Of the 340 remainders, 33.7% (n=116) answered for the CAT, 30.5% (n=105) the CCQ and 34.6% (n=119) the SGRQ. Groups were comparable regarding the demographic and clinical parameters listed above. Moreover, all three groups presented a similar degree of generic HRQL impairment, measured on the VAS, on the EBVS and on the utilities; with overall means of 57.4, 0.62 and 0.70 respectively.

### 3.2 Representativeness of the study sample

**Study participants vs. DMP-Enrollees**

Among the initial sample of 49.686 DMP-COPD enrollees we observed a mean age of 69.4 (11.2) and a share of male individuals of 54.3 %. GOLD-stage could be assessed for 43,992 (88.4%) individuals. Thereof 31.6 *% were GOLD1, 43.4 % GOLD2, 20.0 % GOLD 3 and 5.1% GOLD 4.*

**Responder vs. Non-responder**

25.4% (n = 344) of the surveyed participants answered the questionnaires. Mean age and mean years of DMP participation did not differ significantly between responders and non-responders. However, the portion of men in the responders was higher than in the non-responders (60.6% vs 51.1%) (Table 2).

### 3.3 Questionnaire characteristics/Psychometric values

The time for completing the questionnaires were on average 14, 17, and 30 minutes for CAT, CCQ and SGRQ, and we received 109 (94.0%), 99 (94.3%) and 78 (65.6%) validly answered questionnaires, respectively. None of the questionnaires showed floor or ceiling effects (Table 3). Figure 1 shows the mean generic HRQL values in the two merged GOLD groups. Neither the EBVS nor the German utilities could perfectly depict the HRQL in severe cases; VAS deviated from the value sets.

### 3.4 Pearson correlation coefficients

Correlations between the different HRQL measures and GOLD stage are shown in Table 4. Except for the GOLD stages, all correlations were at least moderate. Disease-specific questionnaires correlated more strongly with COPD severity than generic ones. Regarding the value sets, EBVS presented a higher correlation to the disease-specific measures than utilities.

### 3.5 Additional explanatory power of the disease-specific HRQL questionnaires

After eliminating the CCQ and SGRQ because of lower correlation, fewer valid answers and extended time for answering, we conducted the last analysis with the CAT. Adding the CAT to disease severity and to the EQ-5D domains increases the explanatory value of the model by 0.05 (by 10 %) (Table 5).

## 4.0 Discussion

Our study investigated three different disease-specific questionnaires in a German COPD population, to find a suitable add-on to the EQ-5D-5L. Moreover, two different approaches to value generic

206 HRQL were contrasted. Furthermore we analyzed the additional value of the most suitable disease-
207 specific questionnaire on the VAS.
208 In our analysis, responders and non-responders did not substantially differ in the measured variables
209 and the three HRQL groups (Group CAT, Group CCQ, Group SGRQ) presented comparable
210 demographic and clinical characteristics. Thus, we consider our study population and subgroups as
211 representative for the DMP COPD participants enrolled with AOK Bavaria SHI Fund. Furthermore, our
212 study population showed similar characteristics as the German COPD cohort- COSYCONET [3]- in
213 terms of mean age, share of men in the study population and VAS. COSYCONET applies the less
214 sensitive 3-Level version of the EQ-5D, therefore a comparison of the values health states is not
215 possible. Nevertheless, because of the similarities, we consider our results of relevance for the
216 German COPD population. Furthermore, the COSYCONET study, proves that EQ-5D-3L is suitable to
217 detect COPD-specific impairments. COSYCONET data demonstrated that – compared to lung healthy
218 controls – COPD patients experience a clinically relevant decrement in health-related quality of life
219 [4]We are strongly convinced that this finding is transferable to the EQ-5D-5L as well, even though
220 we did not include lung-healthy controls in our analyses.
221 In our study the response rate for the three different questionnaires did not differ significantly,
222 however the proportion of valid answers was lower in SGRQ suggesting that the complexity and
223 length of this questionnaire were not appropriate for this target group and survey context.
224 Moreover, considering practical applicability as a routine assessment instrument, the calculation of
225 the total score would be difficult and lengthy in a clinical setting. Therefore, we eliminated SGRQ
226 from the list of potential add-on tools for the EQ-5D. CAT and CCQ showed similar results according
227 valid answers (over 90%) and both showed no ceiling or floor effects, suggesting capability to
228 measure changes in HRQL over time. This is important especially in the context of evaluating DMPs
229 and help decision makers to modify DMP concepts if required. Although CCQ showed slightly higher
230 correlation with VAS, CAT showed higher correlation with both value sets increasing the correlation
231 from moderate to high in comparison to CCQ. We assume through the high correlation, that CAT and

EQ-5D both measure HRQL in a similar way. Moreover, the calculation of the CAT score is easier than for the CCQ, and it contains fewer questions, making it more suitable for clinical routine use. Additionally, to assess symptom burden and risk of exacerbation, GOLD guidelines recommend the use of the ABCD assessment tool[20]. This tool is a matrix with exacerbation history and symptom burden on the axes. The ABCD classification forms the basis for pharmacological treatment recommendations and is considered an advancement compared to the solely lung-function-based GOLD classification, since it combines patient reported outcomes with clinical aspects. To group the patients and provide suggestions for different clinical approaches it uses the CAT , making CAT as an important tool for COPD management[20]. Hence, we used the CAT for further analysis as an additional supplement to the generic measure.

The EQ-5D-5L version is sparsely used among COPD patients so far and the few previous studies apply different value sets, making comparison more difficult [24-26].

Nevertheless, Nolan et al. and Lin et al. validated the EQ-5D-5L through two big studies according to convergent validity, discriminative ability and responsiveness to changes and confirmed its usability in the COPD population [24,26]. Our results confirm convergent validity, showing similar if not better results than Nolan et al., however with smaller sample size. Furthermore we have similar floor and ceiling effects [24]. Lin et al. have in their analysis a 36% response rate, which is not directly comparable with ours (different administration of the questionnaires), but confirms the similarity thereof [26]. Therefore our study could further support the validation of the EQ-5D-5L in the COPD population.

Our analysis is, to our knowledge, the first comparison of the two available German value sets in the COPD population. Thus, we can derive crucial insights how different valuation techniques affect the evaluation of HRQL in COPD patients. Corresponding knowledge might support further recommendations how HRQL impairment in COPD patients should be addressed to capture disease burden in a realistic way. The values according the EBVS showed higher accordance with disease-specific measures than the utilities, which were mirrored in higher correlations. Furthermore, EBVS

depicted the VAS more consistently. This implies that the EBVS values the health states closer to patient self-reported health and provide better insights in the HRQL of the diseased than the utilities, nevertheless still making comparison with different disease groups possible. Yet, both value sets have difficulties measuring HRQL in more severe disease states. This underlines the assumption, that generic HRQL measures may not be sensitive enough for severe disease cases without an additional disease-specific, symptom driven HRQL tool.

One solution to this problem is the addition of a disease-specific measure. The CAT was selected for its suitable characteristics and its acceptance as a tool for clinical management. The CAT proved to increase the explanatory power of our model by 10 percent, emphasizing the importance of the combined use of generic and disease-specific measures. As data used in this pilot study only covers a part of the potentially relevant HRQL determinants, a moderate r-squared (0.52) seems acceptable. Since HRQL questionnaires meant to measure a construct containing various aspects, which are hard to quantify (e.g. fear) we did not expect it to highly correlate with clinical parameters. Therefore, the small correlation between GOLD stages, which are based on lung function parameters, and the HRQL measures seem justified. Some studies found similar results in this regard [27]. The slightly higher correlations between disease-specific HRQL and GOLD stages could originate from the fact, that lung function influences generic aspects of life to a lower extent than it influences respiratory symptoms, which are addressed in disease-specific but not generic questionnaires. Hence, the combined use of disease-specific and generic measures could be beneficial.

There are some limitations to our study. According to our study design, the direct comparison of the three different disease-specific questionnaires was not possible. However, since the characteristics of the groups did not differ significantly, one could expect to achieve similar results in a directly comparative setting. We chose this design to ensure that patients' answers are not influenced by previously answered questionnaires. We assumed that the order of the disease-specific questionnaires (if more than one) would have been an important factor and that the valid answers would have decreased with the amount of time needed to finish our survey.

Next, the study design (postal distribution of the questionnaires) is prone to selection bias: Patients with stable COPD might feel more able to complete the questionnaires than those who just experienced an exacerbation. Thus, we assume health-related quality of life is overestimated particularly in the severe GOLD-stages where exacerbations are more likely. However, the main purpose of our study was rather methodological (identify suitable tools to measure health related quality of life in a real-world setting) than content-related (precise estimation of health-related quality of life in the general population of COPD patients). Thus we consider this issue to be of minor concern. Furthermore, a postal survey was the most feasible method to reach the patients and avoid potential response bias.

Another important point is, that the lung function parameters were not taken at the same time as the questionnaire, therefore we cannot account for the difference occurring in the meantime e.g. due to exacerbations. There are proposals that individuals adapt to health changes after a while, therefore we could assume that small health changes only temporarily influenced HRQL and were not decisive for our analysis [28,29]. We acted on the assumption, that individual adept similarly irrespective of GOLD stage. Unfortunately, we cannot validate this hypothesis within our study sample owing to pooling of severity stages, and lacking longitudinal data. It can hence not be fully excluded, that lung function decrease affects individuals in more severe COPD stage more substantially. In this case adaptation processes might – in contrast to our assumption - be different with regard to duration and degree for the different GOLD stages.

Nevertheless, this is one of the first studies using the five level version of the EQ-5D in COPD patients, and the first to present comparison for the two value sets in a German COPD population.

## 5.0 Conclusion

When used in a small real-world sample of COPD patients, the CAT showed a relative good performance as a disease-specific addition to the EQ-5D-5L. It also provides an accepted tool for supporting patient management in a clinical setting. Regarding the use of value sets, the EBVS had

310 better properties to measure quality of life burden compared to the utilities, although both
311 measures has difficulties to differentiate between disease severity groups. Furthermore, the EBVS
312 provides a comparison tool with the general population for patient-relevant outcome. Therefore,
313 the combined use of the EQ-5D and the CAT is seen as a promising approach to best depict HRQL in
314 COPD patients. Further research is needed to underline these results in larger population.
315
316 **List of abbreviations**
317 CAT: COPD Assessment Test
318 COPD: Chronic Obstructive Pulmonary Disease
319 CCQ: Clinical COPD Questionnaire
320 DMP: Disease Management Program
321 EBVS: experience based value set
322 FEV 1 % pred: forced expiratory volume-one second percent predicted
323 mMRC: Modified British Medical Research Council Dyspnea scale
324 SGRQ: St. George's Respiratory Disease Questionnaire
325 SD: Standard deviation
326 VAS: Visual Analog Scale
327 **Declarations**
328 **Ethics approval and consent to participate**
329 The ethic committee of the Ludwig Maximilians University approved the study (Reference number:
330 17-358). Participants provided written informed consent at the time of inclusion in the disease
331 management program.
332 **Consent for publication**
333 Not applicable.
334 **Availability of data and materials**

The datasets generated and analyzed during the current study are not publicly available due to them containing information that could compromise research participant privacy, but are available from the corresponding author on reasonable request.

**Competing interests**

All authors declare that they have no competing interests.

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**Authors' contribution**

All authors were involved in the conception of the research. RL, AS, and LS initiated the project and decided on research questions and study design. FK prepared the dataset. BS designed analyses, programmed the statistical models and drafted the manuscript in close coordination with FK, RL and LS. All co-authors proofread the manuscript critically and approved its final version.

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**Key issues:**

- COPD is associated with impaired health-related quality of life (HRQL)
- HRQL can be measured by generic (for comparisons among disease groups) and disease-specific tools (for comparison within a disease)
- There are various disease-specific questionnaires for this disease area (COPD Assessment Test (CAT), Clinical COPD Questionnaire (CCQ) or St. George's Respiratory Disease Questionnaire (SGRQ)). But there is no consensus, which one deals as the best complementary tool to the generic EQ-5D-5L
- EQ-5D-5L can be valued with two tariffs, the experience based values and the utilities, and their suitability in comparison to the Visual Analogue Scale is not examined yet.
- We evaluated the 3 disease-specific tools and 2 tariffs in a randomly selected cohort of 1,350 patients from a large Statutory Health Insurance Fund (AOK Bavaria) suffering from COPD
- Based on response rates, ceiling and floor effects and explanatory power, we found CAT as the best supplementary tool and the experience based values as the better tariff for EQ-5D-5L