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## Working Paper

# The power of knowledge: A survey on COPD patients' health literacy in Switzerland

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**The power of knowledge: A survey on COPD patients' health literacy in Switzerland**

**Anja Bischof**



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# **The power of knowledge: A survey on COPD patients' health literacy in Switzerland**

**Keywords:** Chronic Obstructive Pulmonary Disease (COPD); Switzerland; Health-related quality of life (HRQoL); Health literacy

**JEL Classification:** I12, I14, I18

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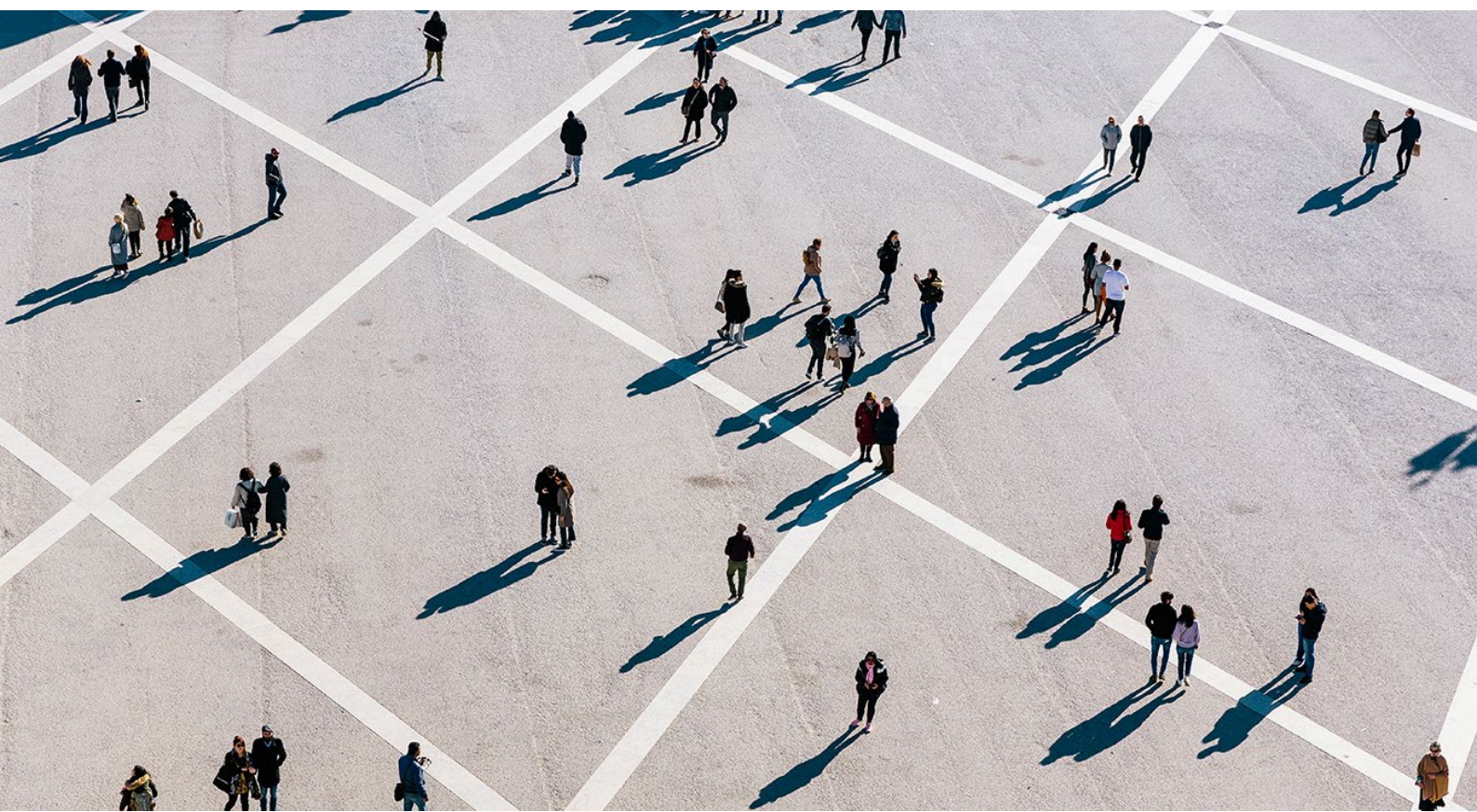
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# The power of knowledge

A survey on COPD patients' health literacy in Switzerland

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Anja Bischof, M.A. HSG  
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St. Gallen, November 29, 2023



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# List of abbreviations

BMI	Body Mass Index
COPD	Chronic Obstructive Pulmonary Disease
DHI	Digital Health Intervention
HL	Health Literacy
HRQoL	Health-Related Quality of Life

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# Abstract

**Background:** Health literacy (HL) is one of the major levers to increase the self-management capabilities of patients suffering from Chronic Obstructive Pulmonary Disease (COPD). However, HL is often insufficient in individuals suffering from COPD. Therefore, this study investigates which factors are associated with HL and whether patients with varying HL states desire different support in digital health interventions to better manage COPD-specific symptoms.

**Methods:** In total, 203 participants completed a web-based survey that collected information on patient's health-related quality of life (HRQoL), possible impairments, and areas of improvement in their daily lives. The HLS-EU-Q16 was applied to assess HL. A chi-square test and an analysis of variances were performed to compare variable characteristics across COPD patients with different HL. An ordinal logistic regression was used to identify variables significantly associated with HL. Based on the survey's responses, the patients' desire for daily support were identified.

**Results:** Of the 203 participants, 53.2% demonstrated sufficient HL, 27.6% indicated problematic HL, and 19.2% displayed inadequate HL. Significant differences in the requirement of support in daily life ( $\chi^2=0.032$ ), length of diagnosis ( $\chi^2=0.015$ ), and confidence in medication intake ( $\chi^2<0.001$ ) were observable. Furthermore, significant differences in age ( $p<0.001$ ), EQ-5D-5L ( $p<0.001$ ), EQ-VAS ( $p<0.001$ ), and CAT ( $p=0.004$ ) were identified. The ordinal logistic regression revealed age and the EQ-5D-5L as significantly associated with HL. COPD patients expressed consistent preferences for support in digital health interventions, irrespective of their HL state.

**Conclusion:** The study reveals that age and HRQoL, represented by the EQ-5D-5L, are significantly associated with HL. Approaches to improving HRQoL might be considered to strengthen HL. Additionally, the study identifies desired support mechanisms for COPD patients when developing digital health interventions for this patient group. Future research could explore the interplay between HRQoL, HL, and self-management and the potential of digital health intervention in this interplay.

**Keywords:** Chronic Obstructive Pulmonary Disease (COPD), Switzerland, Health-related quality of life (HRQoL), Health literacy

# 1 Introduction

Chronic Obstructive Pulmonary Disease (COPD) is the third leading cause of death worldwide in 2019 [1]. In Switzerland, around 400,000 patients suffer from the chronic lung disease [2], which is approximately 5% of the total population. In former times, male patients were more prone to suffer from COPD. However, the prevalence in women has increased and equaled the level of men in 2008 [3]. Typical symptoms are shortness of breath, cough, and sputum [4]. COPD causes an enormous economic burden of CHF 603-847 million in direct costs and CHF 932 million in indirect costs annually in Switzerland [5]. Individuals with a low socioeconomic status are especially prone to the disease [6]. Due to the chronic nature of the disease, patients suffering from COPD must know how to deal with the disease during their daily lives. This ability is known as self-management, which relates to “an individual’s ability to detect and manage symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition” [7]. Furthermore, patient-physician communication is important to foster a basic understanding of the disease, however physicians alone cannot mitigate the problem of non-compliance to treatment due to low self-management capabilities [8].

In the case of COPD, self-management comprises regular physical activity, medication adherence, and smoking cessation [4]. The main aim of self-management is improving or maintaining physical health, decreasing symptom impact and impairments, increasing well-being from an emotional, social, and psychological perspective, and creating effective ties with family, practitioners, and community [9]. One major driver of improved self-management capabilities is health literacy (HL) [10].

HL encompasses the extent of one’s capability to find, understand, and effectively use health information and health services while promoting health and preventing disease [11]. HL is assessed by various internationally validated self-assessment instruments such as the Health Literacy Questionnaire (HLQ) [12], the European Health Literacy Survey Questionnaire (HLS-EU-Q) [13], or the Single Item Literacy Screener (SILS) [14]. HL is especially low among COPD patients [15]. Low HL is associated with worse health outcomes in COPD [16], low medication adherence [8], and limited self-management capabilities [15].

However, supporting patients to navigate through the health care system and misunderstanding information are structural problems in the patient-physician communication. Physicians and nurses often overestimate patients’ HL skills by assuming that the patients can process complex instructions [17–19]. This problem worsens as patients also tend to overestimate their HL [20]. In addition to verbal communication, written disease-related education material remains inaccessible to patients with low HL due to excessively high reading prerequisites or insufficient quality [21, 22]. Furthermore, the literature highlights that patients usually have limited knowledge about their disease [23, 24], directly related to insufficient disease management. To tackle the challenge of patients’ limited health knowledge, self-management resources such as virtual chatrooms are established to strengthen conversations between COPD patients and various stakeholders [25], or information material in facilitated language is provided, such as in Germany [26].

To support COPD patients better in their daily dealing with the disease and the corresponding symptoms, digital health interventions (DHI) are a potential approach. DHIs cover mHealth [27, 28], telemonitoring [29], and telemedicine. This allows providers to remotely assess the patient’s

health status and adapt treatments to individual needs [30, 31]. Furthermore, the patients can access health information themselves and independently monitor their personal condition [27]. Puente-Maestu et al. [32] argue that HL needs to be considered when planning the care of COPD patients – especially when taking a patient-centered approach. Nevertheless, most interventions do not measure HL as an outcome [10]. The principal aim of the DHIs must be to avoid COPD exacerbations (i.e., acute worsening of COPD) leading to hospitalizations and increased mortality [33].

Facilitators for DHI adoption are improved disease understanding and management [34]. Additionally, scalability of interventions is needed to allow DHIs to be cost-effective [33]. Therefore, it becomes crucial to understand better the specific needs of support raised by patients suffering from COPD. As HL highly influences self-management capabilities [35], the intervention's requirements must be distinguished between different HL states. Being aware of different needs between HL states allows for developing more suitable interventions and enhances scalability across patients with different HL states.

Thus, I investigate the following questions in this paper:

- Which factors are associated with higher health literacy?
- What types of support do patients with varying health literacy states desire in digital health interventions to better deal with COPD?

This paper analyzes where differences in HL exist and investigates which factors influence HL. Furthermore, it provides insights on whether patients suffering from COPD desire different types of support to manage their daily lives actively. Understanding this will be a crucial part of building DHIs in the future. This is the first study investigating the need to support COPD patients by directly collecting responses from a tailored survey distributed in Switzerland.

## 2 Methods

### *Survey design*

We designed an online survey using Unipark [36], an online survey software for research conducted at universities and other educational institutions. The survey was developed based on current literature and in collaboration with a chief pulmonologist and a digital health expert. The questionnaire contained different sections dealing with patient's health-related quality of life (HRQoL), possible impairments, and areas of improvement in their daily lives and was structured into five sections: general information, disease-specific questions, need for support, HRQoL, and dealing with COPD. In the questionnaire, we used internationally validated instruments for measuring patients' HRQoL (EQ-5D-5L and EQ-VAS questionnaires) [37–39], patients' disease-specific condition (COPD Assessment Test questionnaire) [39–41], and patients' HL (HLS-EU-Q16) [32, 42] (the survey questions are provided in Supplementary Material 1). The chosen HL questionnaire is the short-form version of the HLS-EU-Q. The instrument collects information on four main HL dimensions: access, understandability, evaluation, and use of health information in the areas of disease prevention and health promotion [13].

The survey was available in German, French, and Italian. Native speakers translated the German version into French and Italian. Furthermore, eight participants checked the survey for understandability and practicability before the collection period. These eight participants were not included in the final sample.

The data was stored on password-protected computers. The order of questions was the same for all respondents. The survey, furthermore, included adaptive items, for example, for smoking and further comorbidities, which were only presented if the participant answered previous questions accordingly. At the bottom of every page, the participant could click a "back" button to adjust responses on previous pages if needed. The survey was designed and reported following the Checklist for Reporting Results of Internet E-Surveys [43].

### *Ethical approval and informed consent*

This survey was submitted to the Ethics Committee Eastern Switzerland and determined to be exempt according to Art 2 (2c) on the Swiss Human Research Act on March 24, 2022. All participants completed the survey voluntarily. The front page stated that the participant's data would be used anonymously, explained the research purpose, and listed host organization details. Before starting the survey, the participants had to agree on having understood the information on the front page, which served as electronic consent. We only collected and stored data anonymously.

### *Participants*

All patients suffering from COPD and living in Switzerland were eligible for participation in the survey. One question dealt with the participant's disease, and the answers were excluded if the participant did not suffer from COPD.

### *Recruitment*

We applied an open survey design and therefore allowed for a convenience sample. The survey was advertised on Facebook in German, French, and Italian (see Supplementary Material 2). A particular challenge of the recruitment was the anonymous collection of the responses. To further promote the recruitment, the following care providers and organizations were contacted and

asked to distribute flyers (see Supplementary Material 3): general practitioners, pulmonologists, pulmonology departments in hospitals, pharmacies, COPD support groups, rehabilitation centers, cantonal lung leagues, and physician networks. However, potential participants were never contacted directly.

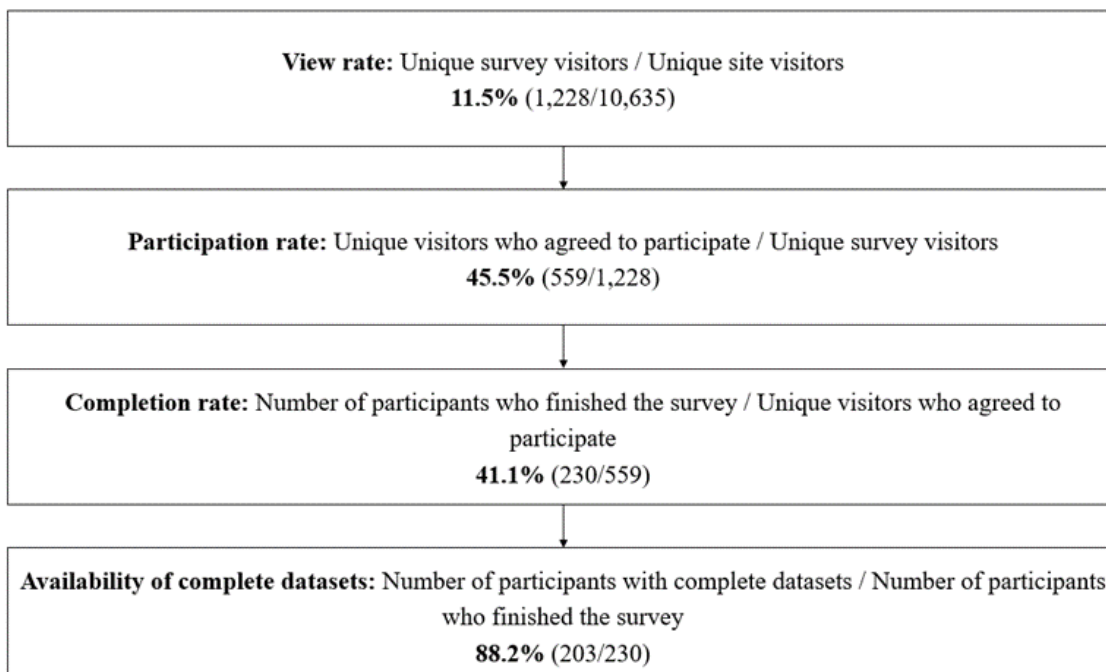
### *Administration*

A link to the survey was provided in the Facebook ad, and a QR code on the flyers directed the participants directly to the survey's landing page. The survey was not administered via email. Participants responded voluntarily, and a lottery with three Swiss holiday (Reka) vouchers for CHF 100 was offered. In addition, participants could reach out to the survey hosts via email to be informed about the study results. The response collection period was from July 1, 2022, to July 31, 2023. The questionnaire consisted of 66 questions distributed over six survey pages. From the server side, all questions were marked as mandatory, and the participant could not reach the next survey page if not all questions were answered on the previous page. IP addresses were not visible for the survey hosts. However, the survey platform Unipark stored IP addresses to deny access to participants if they had already previously filled out the survey.

### *Response rates*

Unipark, the chosen survey collection platform, measured the number of visitors and participants directly. The survey view rate was 11.5% (1,228/10,635), the participation rate was 45.5% (559/1,228), and the completion rate for the overall survey was 41.1% (230/559). In total, 203 survey participants were included in the sample (see Figure 1).

**Figure 1. Survey response rates**



### *Statistical analysis*

To calculate HL for the individual respondents, the thresholds were chosen according to Röthlin et al. [44]. Thereby, three states of HL are possible: “sufficient” (scores 13-16), “inadequate” (scores 9-12), and “problematic” (scores 1-8). First, to characterize the study population, mean values and

standard deviations (95% confidence intervals) for continuous variables, and frequencies and percentages for categorical variables are provided. Second, to analyze differences in the patients' characteristics of participants between HL states, a chi-square test of homogeneity was used for categorical variables, whereas an analysis of variance (ANOVA) was performed to compare the central tendencies of continuous variables. Third, a cumulative odds ordinal logistic regression with proportional odds was applied. As potential confounders, only variables with a  $p < 0.05$  in the chi-square test and the ANOVA were included in the regression. The regression was performed to identify significantly associated variables with HL. All analyses were conducted with IBM-SPSS version 28 [45].

To analyze whether differences in the desire for daily support for dealing with COPD-specific challenges depend on HL states, three areas were inquired: 1) difficulties with COPD, 2) desire type of support, and 3) support with COPD-specific symptoms (see Supplementary Material 1, Questions 27, 28, and 35). The participants had the possibility to choose more than one answer for each question. Subsequently the frequency of the responses was counted to establish a ranking.

## 3 Results

### *Descriptives*

Of the 203 participants, 108 showed sufficient HL, 56 indicated problematic HL, and 39 displayed inadequate HL (see Table 1). Following this, only 53.2% of all participants have a satisfactory HL state. Concerning gender distribution, 128 female, 73 male, and two diverse participants were included. Most of the participants (52.2%) indicated that a professional training is their highest degree of education, followed by compulsory school (17.7%) and higher education (16.7%). 55.7% of the participants indicated a COPD status B, while 32.5% indicated a D-status. Around 28% of the participants claimed they depend on daily support.

38.4% of the participants expressed that they are still smoking despite being diagnosed with COPD, whereas more than half quit smoking. 47.3% of the participants have suffered from COPD for more than five years, and 35% have already been hospitalized due to a COPD exacerbation. While 84.2% of the participants must take medication to cope with COPD-specific symptoms, 22.6% feel insecure about correctly taking the medication. For treatment and further information on COPD, the primary contact person is the specialist or pulmonologist in 52.7% of all cases. 10.3% of participants indicated that they regularly exchange with other COPD patients, and 11.8% participated in a program designed to learn more about COPD and how to deal with it in daily life (called “Living better with COPD”). More than one fourth have already been to outpatient pulmonary rehabilitation, and 57.1% are yearly vaccinated against the flu.

Furthermore, the average participant was 64.9 years old and had a BMI of 26.7 – thus being slightly overweight. 31 participants expressed that they suffer from comorbidities. On average, these participants suffered from 2.68 comorbidities. Regarding self-perceived health status, the EQ-index score showed an average of 0.724. In contrast, the EQ-VAS displayed an average of 61.26. For the disease-specific PRO – measured by CAT – the mean was at 18.88, indicating a medium impact level of the disease on the quality of life. The mean time participants spent filling out the survey was 21 minutes 4 seconds, while the median was 19 minutes 38 seconds. All responses with a time stamp below 12 minutes were excluded.

**Table 1. Descriptives of the survey participants**

Variable	Variable characteristics	Number	(%)
<b>Health Literacy</b>	Sufficient	108	53.2
	Inadequate	56	27.6
	Problematic	39	19.2
<b>Gender</b>	Male	73	36.0
	Female	128	63.1
	Diverse	2	1.0
<b>Education</b>	No school	5	2.5
	Compulsory school	36	17.7
	Professional training	106	52.2

<b>Variable</b>	<b>Variable characteristics</b>	<b>Number</b>	<b>(%)</b>
	Matura	8	3.9
	Higher education	34	16.7
	University degree	14	6.9
<b>COPD status</b>	A	19	9.4
	B	113	55.7
	C	5	2.5
	D	66	32.5
<b>Support in daily life</b>	Yes	57	28.1
	No	146	71.9
<b>Smoking</b>	Yes, daily	61	30.0
	Yes, sometimes	17	8.4
	No longer	104	51.2
	Never	21	10.3
<b>Length of diagnosis</b>	Less than 1 year	33	16.3
	1 to less than 3 years	33	16.3
	3 to less than 5 years	41	20.2
	5 to less than 7 years	45	22.2
	7 to less than 10 years	23	11.3
	Over 10 years	28	13.8
<b>Hospitalized exacerbation</b>	Yes	71	35.0
	No	132	65.0
<b>Taking COPD-specific medication</b>	Yes	171	84.2
	No	32	15.8
<b>Feeling secure in medication intake</b>	Very insecure	24	11.8
	Insecure	22	10.8
	Neutral	37	18.2
	Secure	43	21.2
	Very secure	76	37.4
	I do not take medication	1	0.5
<b>Primary contact person</b>	GP	77	37.9
	Specialist/Pulmonologist	107	52.7
	Hospital	11	5.4
	Other	8	3.9
<b>Exchange with other patients</b>	Yes	21	10.3
	No	182	89.7



Variable	Variable characteristics	Number	(%)
<b>Participation at “Living better with COPD”</b>	Yes	24	11.8
	No	179	88.2
<b>Participation at outpatient pulmonary rehabilitation</b>	Yes	55	27.1
	No	148	72.9
<b>Yearly vaccination against the flu</b>	Yes	116	57.1
	No	87	42.9
		<b>Mean</b>	<b>SD</b>
<b>Age</b>		64.93	10.02
<b>BMI</b>		26.71	6.63
<b>Number of comorbidities*</b>		2.68	1.54
<b>EQ-5D-5L</b>		0.724	0.233
<b>EQ-VAS</b>		61.26	22.38
<b>CAT</b>		18.88	7.67

Legend: SD = Standard deviation; BMI = Body Mass Index; CAT = COPD Assessment Test

\*only 31 participants indicated that they were suffering from comorbidities – therefore, mean and standard deviation were calculated for these 31 participants

### *Differences in distribution of variables' characteristics regarding health literacy*

I grouped the participants according to their HL into sufficient, inadequate, and problematic and compared the distribution of variables' characteristics across the groups and whether these distributions were significantly different. Significant differences in the requirement of support in daily life ( $\chi^2=0.032$ ), length of diagnosis ( $\chi^2=0.015$ ), and confidence in medication intake ( $\chi^2<0.001$ ) were observable (see Table 2). In support in daily life, participants with problematic (38.5%) and inadequate HL (35.7%) indicated that they receive significantly more often help compared to participants with sufficient HL (20.4%). Additionally, participants who are longer than five years diagnosed with COPD had significantly more often sufficient HL (54.6%) compared to people who were diagnosed for fewer years (inadequate: 39.3%; problematic: 37.7%). Lastly, a significant difference in the distribution was observable for feeling secure in medication intake. Participants with sufficient HL (66.6%) indicated feeling confident in medication intake compared to participants with inadequate (48.2%) and problematic HL (51.3%). No significant difference in the distribution of variables' characteristics was observable for any other categorical variable.

**Table 2. Differences in variables' characteristics regarding health literacy**

		<b>Sufficient (n=108)</b>		<b>Inadequate (n=56)</b>		<b>Problematic (n=39)</b>		<b>Chi-square</b>
		<b>Number</b>	<b>(%)</b>	<b>Number</b>	<b>(%)</b>	<b>Number</b>	<b>(%)</b>	
<b>Gender</b>	Male	36	33.3	21	37.5	16	41.0	0.665

		<b>Sufficient (n=108)</b>		<b>Inadequate (n=56)</b>		<b>Problematic (n=39)</b>		<b>Chi- square</b>
		<b>Number</b>	<b>(%)</b>	<b>Number</b>	<b>(%)</b>	<b>Number</b>	<b>(%)</b>	
	Female	70	64.8	35	62.5	23	59.0	
	Diverse	2	1.9	0	0.0	0	0.0	
<b>Education</b>	No school	1	0.9	1	1.8	3	7.7	0.278
	Compul- sory school	19	17.6	8	14.3	9	23.1	
	Professional training	54	50.0	33	58.9	19	48.7	
	Matura	5	4.6	2	3.6	1	2.6	
	Higher edu- cation	18	16.7	9	16.1	7	17.9	
	University degree	11	10.2	3	5.4	0	0.0	
<b>COPD status</b>	A	13	12.0	4	7.1	2	5.1	0.316
	B	56	51.9	34	60.7	23	59.0	
	C	5	4.6	0	0.0	0	0.0	
	D	34	31.5	18	32.1	14	35.9	
<b>Support in daily life</b>	Yes	22	20.4	20	35.7	15	38.5	0.032
	No	86	79.6	36	64.3	24	61.5	
<b>Smoking</b>	Yes, daily	28	25.9	14	25.0	19	48.7	0.059
	Yes, some- times	12	11.1	2	3.6	3	7.7	
	No longer	56	51.9	35	62.5	13	33.3	
	Never	12	11.1	5	8.9	4	10.3	
<b>Length of diagnosis</b>	Less than 1 year	17	15.7	10	17.9	6	15.4	0.015
	1 to less than 3 years	16	14.8	5	8.9	12	30.8	
	3 to less than 5 years	16	14.8	19	33.9	6	15.4	
	5 to less than 7 years	23	21.3	12	21.4	10	25.6	
	7 to less than 10 years	17	15.7	3	5.4	3	7.7	

		<b>Sufficient (n=108)</b>		<b>Inadequate (n=56)</b>		<b>Problematic (n=39)</b>		<b>Chi- square</b>
		<b>Number</b>	<b>(%)</b>	<b>Number</b>	<b>(%)</b>	<b>Number</b>	<b>(%)</b>	
	Over 10 years	19	17.6	7	12.5	2	5.1	
<b>Hospital- ized exacer- bation</b>	Yes	39	36.1	18	32.1	14	35.9	0.872
	No	69	63.9	38	67.9	25	64.1	
<b>Taking medication</b>	Yes	92	85.2	49	87.5	30	76.9	0.351
	No	16	14.8	7	12.5	9	23.1	
<b>Feeling secure in medication intake</b>	Very inse- cure	14	13.0	3	5.4	7	17.9	<0.001
	Insecure	9	8.3	11	19.6	2	5.1	
	Neutral	13	12.0	14	25.0	10	25.6	
	Secure	20	18.5	9	16.1	14	35.9	
	Very secure	52	48.1	18	32.1	6	15.4	
	I do not take medication	0	0.0	1	1.8	0	0.0	
<b>Primary contact person</b>	GP	39	36.1	18	32.1	20	51.3	0.611
	Special- ist/Pul- monologist	59	54.6	32	57.1	16	41.0	
	Hospital	5	4.6	4	7.1	2	5.1	
	Other	5	4.6	2	3.6	1	2.6	
<b>Exchange with other patients</b>	Yes	14	13.0	5	8.9	2	5.1	0.356
	No	94	87.0	51	91.1	37	94.9	
<b>Participa- tion at “Living better with COPD”</b>	Yes	13	12.0	7	12.5	4	10.3	0.941
	No	95	88.0	49	87.5	35	89.7	
<b>Participa- tion at outpatient pulmonary rehabilita- tion</b>	Yes	32	29.6	15	26.8	8	20.5	0.546
	No	76	70.4	41	73.2	31	79.5	

		<b>Sufficient (n=108)</b>		<b>Inadequate (n=56)</b>		<b>Problematic (n=39)</b>		<b>Chi- square</b>
		<b>Number</b>	<b>(%)</b>	<b>Number</b>	<b>(%)</b>	<b>Number</b>	<b>(%)</b>	
<b>Yearly vaccination against the flu</b>	Yes	64	59.3	34	60.7	18	46.2	0.299
	No	44	40.7	22	39.3	21	53.8	

An ANOVA was applied for continuous variables to test for differences in the mean values between the three HL states. I identified significant differences in age ( $p<0.001$ ), EQ-5D-5L ( $p<0.001$ ), EQ-VAS ( $p<0.001$ ), and CAT ( $p=0.004$ ) (see Table 3). According to the post hoc test, participants with sufficient HL were significantly older than participants with inadequate ( $p=0.005$ ) and problematic ( $p=0.002$ ) HL. Participants with sufficient HL expressed significantly better scores in EQ-5D-5L than participants with inadequate ( $p=0.003$ ) and problematic ( $p<0.001$ ) HL. Concerning EQ-VAS, participants with problematic HL stated significantly worse values compared to inadequate ( $p=0.012$ ) and sufficient ( $p<0.001$ ) HL. For the CAT score, participants with sufficient HL showed significantly lower (i.e., better) values compared to inadequate ( $p=0.041$ ) and problematic ( $p=0.010$ ) HL. No significant differences were observable between the groups for mean BMI and the average number of comorbidities.

**Table 3. Differences in mean values regarding health literacy**

	<b>Sufficient (n=108)</b>	<b>Inadequate (n=56)</b>	<b>Problematic (n=39)</b>	<b>F</b>	<b>p- value</b>
	Mean (SD)	Mean (SD)	Mean (SD)		
<b>Age</b>	67.54 (8.85)	62.45 (10.68)	61.28 (10.33)	8.55	<0.001
<b>BMI</b>	26.67 (6.76)	27.33 (6.37)	25.96 (6.72)	0.49	0.614
<b>Number of comorbidities</b>	2.89 (1.23)	2.22 (1.30)	2.75 (3.10)	0.553	0.581
<b>EQ-5D-5L</b>	0.793 (0.200)	0.6714 (0.215)	0.610 (0.280)	10.81	<0.001
<b>EQ-VAS</b>	65.27 (21.19)	62.11 (21.05)	48.95 (23.53)	8.226	<0.001
<b>CAT</b>	17.23 (7.53)	20.30 (7.70)	21.38 (7.07)	5.801	0.004

### *Factors influencing health literacy*

For the logistic regression, the control variables were support in daily life, length of diagnosis, feeling secure in medication intake, age, EQ-5D-5L, EQ-VAS, and CAT. These variables were chosen due to their significant values ( $p<0.05$ ) in the previously conducted chi-square test and ANOVA. The logistic regression revealed that age and the EQ-5D-5L are significantly associated with HL (see Table 4). A lower odds ratio signifies a higher (better) HL. Thus, the odds ratio for age ( $OR= -0.042$ ;  $p=0.011$ ) and the EQ-5D-5L ( $OR= -2.166$ ;  $p=0.017$ ) express a higher likelihood of

sufficient HL to be present. No significant associations were observable for any other included variable. The model achieved a pseudo-R-squared of 0.260.

**Table 4. Regression table for identifying associations with health literacy**

	Odds ratio	Confidence intervals	Significance (p-value)
<b>Support in daily life</b>	0.625	-0.098 – 1.349	0.090
<b>Length of diagnosis</b>			
Less than 1 year	0.479	-0.655 – 1.614	0.408
1 to less than 3 years	0.915	-0.200 – 2.029	0.108
3 to less than 5 years	0.453	-0.630 – 1.536	0.412
5 to less than 7 years	0.823	-0.217 – 1.863	0.121
7 to less than 10 years	-0.417	-1.716 – 0.881	0.529
<b>Feeling secure in medication intake</b>			
Very insecure	-0.791	-4.630 – 3.048	0.686
insecure	-1.070	-4.870 – 2.729	0.581
Neutral	-0.561	-4.346 – 3.224	0.771
Secure	-0.631	-4.394 – 3.131	0.742
Very secure	-1.406	-5.191 – 2.378	0.466
<b>Age</b>	-0.042	-0.074 – -0.010	0.011
<b>EQ-5D-5L</b>	-2.166	-3.950 – -0.382	0.017
<b>EQ-VAS</b>	-0.007	-0.023 – 0.008	0.364
<b>CAT</b>	-0.018	-0.069 – 0.033	0.494

Reference categories: support in daily life: no; diagnosis in years: over 10 years; confidence in medication intake: very confident

#### *Differences in desire for support*

The “top three” answers of the patients’ desire for daily support are listed in Table 5 according to the HL states. Concerning difficulty in dealing with COPD, participants of all HL states indicated facing most difficulties in the limited movement possibilities, followed by a lack of chance to cure and fears about the future due to disease and changing living circumstances for sufficient HL. Compared to participants with inadequate and problematic HL, they indicated most difficulties in dealing with fears about the future due to the disease and, the lack of chance of cure (inadequate) and insufficient sleep quality (problematic). Thus, independent of HL, participants perceive the same difficulties in dealing with COPD.

Regarding the wish for support, the picture is even more similar. Independent of the HL state, the participants wished for support through regular advice and information dealing with COPD, followed by inputs for regular exercises to decrease the COPD symptom level. Third ranks in all HL states the desire to compare their health status with the average COPD patient. Also, for the support in dealing with COPD-specific symptoms, the highest symptom burdens are breathlessness,

anxiety/depression, and tiredness across all HL states. Concludingly, no differences in needs for support were observable between HL states – the needs were almost identical.

**Table 5. Difficulty in dealing with COPD, wish for support in daily life, and support with symptoms per HL group**

	Sufficient (n=108)	Inadequate (n=56)	Problematic (n=39)
<b>Difficulty in dealing with COPD</b>	<ol style="list-style-type: none"> <li>1. Limited movement possibilities (48.1%)</li> <li>2. Lack of chance to cure (38.9%)</li> <li>3. Fears about future due to disease (31.5%) / Changing living circumstances (31.5%)</li> </ol>	<ol style="list-style-type: none"> <li>1. Limited movement possibilities (62.5%)</li> <li>2. Fears about future due to disease (58.9%)</li> <li>3. Lack of chance to cure (42.9%)</li> </ol>	<ol style="list-style-type: none"> <li>1. Limited movement possibilities (69.2%)</li> <li>2. Fears about future due to disease (59.0%)</li> <li>3. Insufficient sleep quality (41.0%)</li> </ol>
<b>Wish for support in daily life</b>	<ol style="list-style-type: none"> <li>1. Regular advice and information dealing with COPD (36.1%)</li> <li>2. Regular exercises to decrease COPD symptom level (28.7%)</li> <li>3. Comparing own health status with average COPD patient (18.5%)</li> </ol>	<ol style="list-style-type: none"> <li>1. Regular advice and information dealing with COPD (57.1%)</li> <li>2. Regular exercises to decrease COPD symptom level (44.6%)</li> <li>3. Comparing own health status with average COPD patient (33.9%)</li> </ol>	<ol style="list-style-type: none"> <li>1. Regular advice and information dealing with COPD (64.1%)</li> <li>2. Regular exercises to decrease COPD symptom level (48.7%)</li> <li>3. Comparing own health status with average COPD patient (30.9%)</li> </ol>
<b>Support with symptoms</b>	<ol style="list-style-type: none"> <li>1. Breathlessness (50.0%)</li> <li>2. Anxiety/depression (33.3%)</li> <li>3. Tiredness (29.6%)</li> </ol>	<ol style="list-style-type: none"> <li>1. Breathlessness (51.8%)</li> <li>2. Tiredness (39.3%)</li> <li>3. Anxiety/depression (37.5%)</li> </ol>	<ol style="list-style-type: none"> <li>1. Breathlessness (69.2%)</li> <li>2. Tiredness (53.8%)</li> <li>3. Anxiety/depression (51.3%)</li> </ol>

## 4 Discussion

The sample included 203 participants, of which 108 showed sufficient HL, 56 indicated inadequate HL and 39 expressed problematic HL. Evidence exists that people suffering from COPD are often affected by low HL [16] – in this case, around 46% of the participants. Furthermore, the sample consisted of 63% female participants. Based on current research, men are no longer exclusively affected by COPD, but more and more women suffer from the disease. However, women often remain underdiagnosed [46] due to various problems, such as women being less frequently referred to pulmonologists or receiving spirometry testing [47, 48]. Additionally, women tend to experience symptoms such as fatigue or depression, which are indicators of other diseases as well [49].

Additionally, the participants in the collected sample display more often B and D COPD status – indicating that they suffer from a worse CAT score. Lower HL is associated with higher (i.e., worse) CAT scores [50]. Although Omachi et al. [51] claim that lower HL is associated with more severe COPD status, no significant differences between HL states are observable in the presented sample. Additionally, the sample encompassed a broad range of educational levels, with most participants having finished a professional training (52.2%), followed by compulsory school (17.7%) and higher education (16.7%). This represents a balanced sample, as in Switzerland, 41.2% conduct a professional training, followed by 15% receiving a higher education degree and 13.9% finishing compulsory school [52].

Significant differences were observable in the sample for the length of diagnosis and feeling secure in the medication intake between the HL states. Participants with sufficient HL were longer diagnosed with COPD compared to the other two HL states. Gysels and Higginson [53] claimed that patients develop better HL over time as they develop an understanding of their symptoms and become able to understand changes in the environment or the body and take proper counteracting measures. Also, Lu et al. [54] highlighted in their study that a longer disease duration is positively associated with better HL and thus leading to higher self-efficacy of managing the disease.

Furthermore, 66% of participants with sufficient HL indicated feeling confident in medication intake, whereas only 48.2% of participants with inadequate and 51.3% with problematic HL expressed the same feeling. Interestingly, proportionally more participants with problematic HL felt secure in medication intake compared to participants with adequate HL. This finding might be explained with the Dunning-Kruger effect, where people with lower HL overestimate their capabilities of understanding and taking the medication correctly [19, 20, 55]. Nevertheless, the proportion of participants feeling secure in medication intake was rather low across all HL states, while COPD patients with higher HL are more adherent to medication intake [56].

Concerning the posed research questions, the focus of the first research question was whether significantly associated factors with patients' HL are identifiable. The ordinal logistic regression reveals that age and the EQ-5D-5L are significantly associated with HL. Compared to other studies, no clear tendency of the association of age with HL in COPD patients is derived in the literature. While some studies indicated that there is no significant association of age with HL [16, 57], others highlighted a significant negative association between these two variables [58, 59]. Regarding HRQoL (represented by EQ-5D-5L and EQ-VAS) and the disease-specific condition (measured by CAT), significant differences between HL states were observable. These values were all most

favorable for participants with sufficient HL, i.e., higher HRQoL and lower disease-specific burden than the other two HL states. Results in line with this study are found in literature [50, 58, 60]. Better HRQoL is positively associated with better HL. Furthermore, Fischer et al. [50] highlighted that higher HL leads to a lower CAT. The EQ-5D-5L is significantly associated with better HL as also shown in Stollefson et al. [58] – thus, strengthening the relation between HRQoL and HL even more.

The second research question dealt with differences in the desire for support by respecting the COPD patients' HL. Although participants differed heavily in their HL, their difficulties in dealing with COPD, requirements for support in daily life, and disease-specific symptoms were almost similar, and no differences across groups were observable. According to this study, study participants perceived most difficulties in the limited movement possibilities and the fears about the future due to the disease. They wished for support in the form of regular advice and information on how to deal with COPD-specific symptoms, followed by regular exercise to decrease the symptom burden and the possibility of comparing their health status with other COPD patients. Also, the participants' perception of managing the disease-specific burden were similar independent of the HL states. Due to the similar requirements across HL states, scalability and cost-effectiveness of DHIs potentially increase [33]. Based on the survey's direct derivation of support options, patients' acceptability of the DHI may be enhanced since it reflects directly on the patients' support requirements.

This study faces two main limitations: 1) a potential bias in the sample as the survey was conducted online and participants were mainly recruited through Facebook advertisements, and 2) the assessment of HL depended on patients' reported information. The first limitation may be established due to the online survey form and the main recruitment strategy through Facebook. Thus, only people with access to the Internet and a Facebook account were mainly targeted. However, since Internet coverage is almost entirely provided in Switzerland and Facebook is still one of the major social media platforms for baby-boomer and earlier generations, I believe this limitation has only minor influence on the sample's recruitment. Furthermore, future health interventions to strengthen HL and self-management capabilities will more extensively use digital approaches, which precondition patients to interact with digital tools. The second limitation refers to the patient's self-report of HL, and their overestimation of their HL capabilities. However, using an internationally validated instrument, the HLS-EU-Q16, any bias of patients' overestimating their HL capabilities should be reduced to a minimum.



## 5 Conclusion

This study highlights significant differences in the amount of support in daily life, length of diagnosis, feeling secure in medication intake, age, and HRQoL across COPD patients with different HL states. Participants with sufficient HL receive less support daily, feel more secure in medication intake, are older, have a higher HRQoL, and indicate less disease-specific impact on health. Furthermore, the ordinal logistic regression reveals that higher age and better HRQoL significantly increase the likelihood of enhanced HL.

Additionally, this study derives desired supportive mechanisms for daily life, such as regular advice on COPD treatment and exercises on coping with COPD-specific symptoms. It further reveals that COPD patients independent of their HL are struggling with similar symptoms such as breathlessness, anxiety/depression, and tiredness. Thus, these insights guide the development of mechanisms being implemented in DHIs. Furthermore, future research may build on the findings of this study, aiming to influence patients' self-perceived quality of life to prove whether an improved HRQoL has an impact on HL and develop supporting mechanisms to enhance patients' self-management capabilities. This study contributes to existing evidence by highlighting the association of age and HRQoL with HL. As patients' HL is an important lever for increased self-management capabilities, it also strengthens the ability to cope with COPD daily. Therefore, it is essential to assess patients' HL regularly and aim to improve it in case patients display inadequate or problematic HL.

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# Supplementary Material

## Supplementary Material 1: Survey questionnaire

### **Identifikation des Unterstützungsbedarfs von Patient:innen mit COPD zur Entwicklung eines Digital Health Assistants**

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Geschätzte Teilnehmerinnen und Teilnehmer

Vielen Dank, dass Sie sich die Zeit für unsere Umfrage nehmen. Ziel der Umfrage ist es ein vertieftes Verständnis Ihrer alltäglichen Herausforderungen mit COPD zu erhalten. Ihre Rückmeldungen helfen uns neue Gesundheitsdienstleistungen zu entwickeln, die Sie zukünftig besser im Alltag mit COPD unterstützen. Die Umfrage dauert ca. 10-20 Minuten.

Ihre Daten werden vertraulich und anonym behandelt. Ihre Antworten dienen ausschliesslich obengenanntem Zweck und werden nicht an Dritte weitergereicht. Nach Abschluss der Forschungsarbeit werden sämtliche Daten vernichtet.

Unter allen teilnehmenden Personen verlosen wir am Ende der Umfrage 3 Reka-Gutscheine im Wert von je CHF 100.

Bei Fragen oder technischen Schwierigkeiten wenden Sie sich gerne an Anja Bischof (E-Mail: XXX, Tel: XXX).

0. Haben Sie die Voraussetzungen zur Teilnahme an der Umfrage zum Unterstützungsbedarf im Umgang mit COPD verstanden und stimmen Sie den Bedingungen zu?
- ... Ja, ich stimme zu.
  - ... Nein, ich stimme nicht zu.

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#### **Allgemeine Angaben**

*In diesem ersten Abschnitt bitten wir Sie um einige persönliche Angaben.*

1. Bitte geben Sie Ihr Geschlecht an.
- ... Männlich

... Weiblich

... Divers

2. Bitte geben Sie Ihr Geburtsjahr an: .....
3. Bitte geben Sie Ihre Grösse in cm an: ..... cm
4. Bitte geben Sie Ihr Gewicht in kg an: ..... kg
5. Bitte geben Sie Ihren höchsten Abschluss an.
  - ... Kein Schulabschluss
  - ... Obligatorische Schule
  - ... Lehrabschluss
  - ... Matura/Abitur
  - ... Höhere Berufsausbildung (HF)
  - ... Hochschulabschluss (Bachelor/Master/Doktorat)
6. Rauchen Sie?
  - ... Ja, täglich
  - ... Ja, gelegentlich
  - ... Nein, nicht mehr
  - ... Nein, noch nie
    - a. Falls ja, wie viele Zigaretten (bzw. Zigarren/Pfeifen) pro Tag rauchen Sie?  
..... (*Anzahl eingeben*)
    - b. Falls ja, seit wie vielen Jahren rauchen Sie?  
..... (*Jahre eingeben*)
    - c. Falls gelegentlich, wie viele Zigaretten (bzw. Zigarren/Pfeifen) pro Woche?  
..... (*Anzahl eingeben*)
    - d. Falls gelegentlich, seit wie vielen Jahren rauchen Sie?  
..... (*Jahre eingeben*)
    - e. Falls nicht mehr, wie viele Zigaretten (bzw. Zigarren/Pfeifen) haben Sie pro Woche geraucht?  
..... (*Anzahl eingeben*)
    - f. Falls nicht mehr, wie viele Jahre haben Sie geraucht?  
..... (*Jahre eingeben*)

7. Haben Sie bereits einmal an einem Rauchstopp-Programm teilgenommen?
- ... Ja
  - ... Nein
    - a. Falls Sie bereits an einem Rauchstopp-Programm teilgenommen haben, von welcher Art war dieses?  
*(Mehrfachantwort möglich)*
      - ... Professionelle Rauchstopp-Beratung
      - ... Rauchstopp-App
      - ... Hypnose oder Akupunktur
      - ... Entspannungstechniken wie autogenes Training oder Yoga
      - ... Andere: .....
      - ... Ich habe noch nie an einem Rauchstopp-Programm teilgenommen.
    - b. An wie vielen Rauchstopp-Programmen haben Sie bereits teilgenommen?  
*Bitte geben Sie die Anzahl in ganzen Zahlen an.*  
..... (Anzahl eingeben)
8. Bitte geben Sie die Grösse Ihres Wohnorts an:
- ... < 5'000 Einwohner
  - ... > 5'000 – 15'000 Einwohner
  - ... > 15'000 – 50'000 Einwohner
  - ... > 50'000 Einwohner
9. Wie sieht Ihre Wohnsituation zurzeit aus?
- ... Zu Hause mit Lebens- bzw. Ehepartner/in
  - ... Zu Hause mit anderen Angehörigen
  - ... Zu Hause allein
  - ... Betreutes Wohnen
  - ... Andere: .....
10. *Wenn zu Hause mit Lebens- bzw. Ehepartner/in oder Angehörigen angegeben wurde:* Raucht eine Person, welche mit Ihnen im gleichen Haushalt lebt?
- ... Ja
  - ... Nein



11. Sind Sie zurzeit auf Hilfe zur Bewältigung Ihres Alltags angewiesen?

- ... Ja
- ... Nein

12. Von wem erhalten Sie Hilfe?

*(Mehrfachantwort möglich)*

- ... Angehörige
- ... Freunde/Nachbarn
- ... Haushaltshilfe
- ... SPITEX oder ähnliche Dienstleister
- ... Andere: .....
- ... Ich erhalte keine Hilfe.

13. Haben Sie Haustiere?

- ... Ja (Bitte geben Sie die Art Ihres Haustiers an – z.B. Hund, Katze, Vogel, etc.)  
Welche? .....
- ... Nein

---

### Fragen zur Krankheit

*In diesem Abschnitt werden Ihnen einige Fragen zu Ihrer Krankheit gestellt.*

14. An welcher chronischen Lungenkrankheit leiden Sie?

*(Mehrfachantwort möglich)*

- ... COPD
- ... Asthma
- ... Weiss ich nicht
- ... Andere Erkrankung: .....

15. Kennen Sie Ihr Stadium der COPD?

- ... Ja
- ... Nein

a. Falls ja, in welchem Stadium befinden Sie sich?

*Hinweis: Durch Einteilung in COPD-Stadien lassen sich der Schweregrad und mögliche Veränderungen im Verlauf der Krankheit gut dokumentieren. Kombination aus*

*Buchstabe und Zahl möglich.*

... A

... B

... C

... D

... 1

... 2

... 3

... 4

16. Wie geht es Ihnen mit Ihrer COPD? *(Bitte geben Sie für jede der folgenden Aussagen an, was derzeit am besten auf Sie zutrifft. Kreuzen Sie (X) in jeder Zeile nur eine Möglichkeit an.)*

Ich huste nie	0	1	2	3	4	5	Ich huste ständig
Ich bin überhaupt nicht verschleimt	0	1	2	3	4	5	Ich bin völlig verschleimt
Ich spüre keinerlei Engegefühl in der Brust	0	1	2	3	4	5	Ich spüre ein sehr starkes Engegefühl in der Brust
Wenn ich bergauf oder eine Treppe hinaufgehe, komme ich nicht außer Atem	0	1	2	3	4	5	Wenn ich bergauf oder eine Treppe hinaufgehe, komme ich sehr außer Atem
Ich bin bei meinen häuslichen Aktivitäten nicht eingeschränkt	0	1	2	3	4	5	Ich bin bei meinen häuslichen Aktivitäten sehr stark eingeschränkt
Ich habe keine Bedenken, trotz meiner Lungenerkrankung das Haus zu verlassen	0	1	2	3	4	5	Ich habe wegen meiner Lungenerkrankung große Bedenken, das Haus zu verlassen
Ich schlafe tief und fest	0	1	2	3	4	5	Wegen meiner Lungenerkrankung schlafe ich nicht tief und fest
Ich bin voller Energie	0	1	2	3	4	5	Ich habe überhaupt keine Energie

17. Vor wie vielen Jahren wurde COPD bei Ihnen diagnostiziert?

... Unter 1 Jahr

... 1 bis unter 3 Jahre

... 3 bis unter 5 Jahre

... 5 bis unter 7 Jahre

... 7 bis unter 10 Jahre

... Über 10 Jahre

18. Gab es schon einmal einen stationären Aufenthalt im Krankenhaus aufgrund von COPD?

... Ja

... Nein

19. Falls Sie bereits einen stationären Aufenthalt im Krankenhaus aufgrund Ihrer COPD hatte, wie lange ist der letzte her?

... Unter 6 Monate

... 6 Monate bis unter 1 Jahr

... 1 bis unter 2 Jahre

... Über 2 Jahre

... Ich hatte noch nie einen stationären Aufenthalt aufgrund meiner COPD.

20. Nehmen Sie verschriebene Medikamente zur Eindämmung der Symptome Ihrer COPD?

... Ja

... Nein

21. Wie sicher fühlen Sie sich bei der Medikamenteneinnahme in Bezug auf den Einnahmezeitpunkt, die richtige Dosierung, etc.? (1 = sehr unsicher; 5 = sehr sicher)

..... (Zahl eingeben)

22. Wer ist Ihre primäre Ansprechperson, wenn es um Ihre COPD geht?

... Hausarzt

... Facharzt/Pneumologe (Lungenarzt)

... Spital

... Andere: .....

---

### Fragen zum Unterstützungsbedarf

*Es folgen nun einige Fragen zu den Herausforderungen mit Ihrer Krankheit. Ebenfalls können Sie Bereiche angeben, in denen Sie sich vermehrt Unterstützung wünschen.*

23. Sind Sie in regelmässigen Austausch mit anderen COPD-Betroffenen?  
... Ja  
... Nein
24. Nehmen Sie am Selbstmanagement-Coaching Programm «Besser Leben mit COPD» der Lungenliga teil oder haben Sie bereits daran teilgenommen?  
... Ja  
... Nein
25. Nehmen Sie an einer ambulanten pulmonalen Rehabilitation (APR) teil bzw. haben Sie bereits daran teilgenommen?  
... Ja  
... Nein
26. Lassen Sie sich jährlich gegen die Grippe impfen?  
... Ja  
... Nein
27. Wo bestehen zurzeit Schwierigkeiten im Umgang mit COPD? (*Mehrfachantwort möglich*)  
... Häufung von ärztlichen Terminen  
... Regelmässige Medikamenteneinnahme  
... Mangelhafte Schlafqualität  
... Eingeschränkte Bewegungsmöglichkeiten  
... Fehlende Informationsgrundlage  
... Identifikation der zuständigen Fachstellen  
... Fehlende Heilungschancen  
... Unverständnis aus dem persönlichen Umfeld  
... Soziale Isolation  
... Bedarf an Hilfe/Unterstützung für alltägliche Tätigkeiten  
... Umgang mit Begleiterkrankungen  
... Nicht-Akzeptanz der Krankheit («Ich hadere mit mir selbst.»)  
... Veränderung der Lebensumstände

... Zukunftsängsten aufgrund der Erkrankung

... Andere Herausforderungen:

.....  
.....

28. Im Umgang mit welchen Symptomen Ihrer COPD wünschen Sie sich Unterstützung? *(Mehrfachantwort möglich)*

... Atemnot

... Husten

... Auswurf

... Abgeschlagenheit/Angstzustände/Depression

... Bewegungsmangel

... Müdigkeit

... Kein Unterstützungsbedarf

... Sonstiges:

.....  
.....

29. Leiden Sie an weiteren chronischen Erkrankungen?

*Hinweis: Eine chronische Erkrankung wird als ein langfristiger, nicht- oder nur schwer-heilbarer Krankheitszustand bezeichnet.*

... Ja

... Nein

a. Falls ja, kreuzen Sie die entsprechenden bitte an. *(Mehrfachantwort möglich)*

... Koronare Herzerkrankung

... Herzinsuffizienz (Herzschwäche)

... Bronchialkarzinom

... Bluthochdruck

... Angststörung

... Depression

... Muskelschwund (Atrophie)

... Knochenschwund (Osteoporose)

... Metabolisches Syndrom

... Diabetes Mellitus Typ 1

- ... Diabetes Mellitus Typ 2
- ... Gewichtsverlust
- ... Anämie
- ... Rückenschmerzen
- ... Andere: .....

*Hinweis: Falls Frage 29 mit «ja» beantwortet wurde, dann beantworten Sie bitte die Fragen 30-34 ebenfalls. Ansonsten gehen Sie bitte direkt zu Frage 35 weiter.*

30. Wie gut fühlen Sie sich über die zuvor angegebenen chronischen Erkrankungen informiert? (1 = ich besitze keine Information; 5 = ich besitze alle benötigten Informationen)

..... (Zahl eingeben)

31. Sind die Informationsmaterialien, die Sie kennen und verwenden, verständlich in Bezug auf Ihre zuvor angegebenen chronischen Erkrankungen? (1 = überhaupt nicht verständlich; 5 = komplett verständlich)

..... (Zahl eingeben)

32. Wie kommen Sie zurzeit mit den zuvor angegebenen chronischen Erkrankungen zurecht?

(1 = überhaupt nicht; 5 = sehr gut)

..... (Zahl eingeben)

33. Wie gut fühlen Sie sich von Ihrem Hausarzt/Facharzt bezüglich der zuvor angegebenen chronischen Erkrankungen betreut? (1 = überhaupt nicht; 5 = sehr gut)

..... (Zahl eingeben)

34. Wünschen Sie sich im Umgang mit den zuvor angegebenen chronischen Erkrankungen weitere Unterstützung?

... Ja

... Eher ja

... Unentschlossen

... Eher nein

... Nein

35. Welche Arten der Unterstützung wünschen Sie sich in Bezug auf Ihre COPD sowie auf die zuvor angegebenen chronischen Erkrankungen (*nur falls zuvor angegeben*)?  
(*Mehrfachantwort möglich*)

- ... Unterstützung bei der Vereinbarung von Arztterminen
- ... Identifikation der zuständigen Fachstelle je nach Anliegen
- ... Erinnerung an Arzttermine
- ... Erinnerung an die Medikamenteneinnahme
- ... Erinnerung an weitere unterstützende Massnahmen zum Umgang mit COPD wie
  - bspw. jährliche Grippeimpfung
- ... Regelmässige Tipps und Informationen zum Umgang mit COPD
- ... Regelmässige Tipps und Informationen zum Umgang mit weiteren chronischen Erkrankungen
- ... Regelmässige Übungen, um Symptome von COPD zu lindern (z.B. Erinnerung an gesunde Ernährung, regelmässige Bewegung, etc.)
- ... Regelmässige Übungen, um Symptome von den weiteren chronischen Krankheiten zu lindern
- ... Unterstützung beim Rauchstopp
- ... Austauschmöglichkeiten mit weiteren Betroffenen
- ... Vergleichsmöglichkeiten des eigenen Gesundheitszustandes zum durchschnittlichen COPD-Patienten
- ... Hilfestellungen für Angehörige oder Pflegende
- ... Unterstützung bei der Kommunikation mit der Krankenkasse
- ... Unterstützung beim Bezahlen von Rechnungen
- ... Kochen bzw. Sicherstellen einer gesunden Ernährung
- ... Sonstiges:
  - .....
  - .....

36. Denken Sie, dass sich eine Verhaltensänderung Ihrerseits positiv auf Ihre COPD auswirken kann?

*Hinweis: Im Zusammenhang mit dieser Umfrage wird unter Verhaltensänderung jene Veränderung von Gewohnheiten betrachtet, die sich positiv auf die Gesundheit auswirken, wie bspw. mehr Bewegung, gesunde Ernährung, genügend Schlaf, striktes Befolgen von Therapieplänen, Wissenserwerb zur Krankheit etc.*

- ... Ja
- ... Eher ja
- ... Unentschlossen
- ... Eher nein
- ... Nein

37. Sind Sie zur Verbesserung Ihrer COPD zu einer Verhaltensänderung bereit?

- ... Ja
- ... Eher ja
- ... Unentschlossen
- ... Eher nein
- ... Nein

38. *Falls weitere chronische Erkrankungen angegeben:* Denken Sie, dass sich die Verhaltensänderungen auch positiv auf Ihre anderen chronischen Erkrankungen auswirken kann?

- ... Ja
- ... Eher ja
- ... Unentschlossen
- ... Eher nein
- ... Nein

a. Falls ja, sind Sie zur Verbesserung Ihrer weiteren chronischen Erkrankungen zu einer Verhaltensänderung bereit?

- ... Ja
- ... Eher ja
- ... Unentschlossen
- ... Eher nein
- ... Nein

39. Nutzen Sie Ihr Smartphone regelmässig?

- ... Ja
- ... Nein



40. Falls ja: Wie oft verwenden Sie Ihr Smartphone?

- ... Mehrmals täglich
- ... Einmal am Tag
- ... Mehrmals in der Woche
- ... Einmal in der Woche
- ... Seltener

41. Besitzen Sie eine Smartwatch?

*Hinweis: Eine Smartwatch ist eine Armbanduhr, die über zusätzliche Sensoren verfügt, welche beispielsweise Ihren Puls oder Ihre Schrittzahl messen.*

- ... Ja
- ... Nein

42. Nutzen Sie digitale Lösungen zur Unterstützung im Umgang mit Ihrer COPD?

*Hinweis: Mit digitalen Lösungen sind in diesem Kontext Handy-Apps oder Wearables/Smartwatches/andere Tracking Geräte (kleine tragbare Computer) gemeint. Dabei erhalten Sie Informationen zur Krankheit oder Sie verfolgen damit die Entwicklung Ihres Gesundheitszustandes über einen gewissen Zeitraum.*

- ... Ja
- Welche? .....
- ... Nein

43. Wären Sie bereit, eine digitale Lösung zur Unterstützung im Umgang mit COPD auszuprobieren?

- ... Ja
- ... Eher ja
- ... Unentschlossen
- ... Eher nein
- ... Nein

*Hinweis: Falls Frage 29 mit «ja» beantwortet wurde, dann beantworten Sie bitte die Fragen 44 & 45 ebenfalls. Ansonsten gehen Sie bitte direkt weiter zu Frage 46.*

44. Nutzen Sie bereits digitale Lösungen zur Unterstützung im Umgang mit Ihren weiteren chronischen Erkrankungen?

... Ja

... Nein

a. Falls ja, welche? (*freie Texteingabe*)

.....

...

45. Wünschen Sie sich ebenfalls Unterstützung im Umgang mit den zuvor angegebenen chronischen Krankheiten?

... Ja

... Eher ja

... Unentschlossen

... Eher nein

... Nein

---

### Fragen zur Lebensqualität

*In dieser kurzen Sequenz bitten wir Sie Ihre Lebensqualität einzuschätzen.*

46. Wie hoch schätzen Sie Ihre Lebensqualität ein? (0 = schlecht möglichst, 100 = bestmöglich)

..... (*Zahl eingeben*)

47. Bitte kreuzen Sie unter jeder Überschrift DAS Kästchen an, das Ihre Gesundheit HEUTE am besten beschreibt.

a. **Beweglichkeit/Mobilität**

... Ich habe keine Probleme herumzugehen

... Ich habe leichte Probleme herumzugehen

... Ich habe mässige Probleme herumzugehen

... Ich habe starke Probleme herumzugehen

... Ich bin nicht in der Lage herumzugehen

b. **Für sich selbst sorgen**

... Ich habe keine Probleme, mich selbst zu waschen oder anzuziehen

... Ich habe leichte Probleme, mich selbst zu waschen oder anzuziehen

... Ich habe mässige Probleme, mich selbst zu waschen oder anzuziehen

- ... Ich habe grosse Probleme, mich selbst zu waschen oder anzuziehen
  - ... Ich bin nicht in der Lage, mich selbst zu waschen oder anzuziehen
  - c. **Alltägliche Tätigkeiten**  
(z.B. Arbeit, Studium, Hausarbeit, Familien- und Freizeitaktivitäten)
    - ... Ich habe keine Probleme, meinen alltäglichen Tätigkeiten nachzugehen
    - ... Ich habe leichte Probleme, meinen alltäglichen Tätigkeiten nachzugehen
    - ... Ich habe mässige Probleme, meinen alltäglichen Tätigkeiten nachzugehen
    - ... Ich habe grosse Probleme, meinen alltäglichen Tätigkeiten nachzugehen
    - ... Ich bin nicht in der Lage, meinen alltäglichen Tätigkeiten nachzugehen
  - d. **Schmerz/Körperliche Beschwerden**
    - ... Ich habe keine Schmerzen oder Beschwerden
    - ... Ich habe leichte Schmerzen oder Beschwerden
    - ... Ich habe mässige Schmerzen oder Beschwerden
    - ... Ich habe starke Schmerzen oder Beschwerden
    - ... Ich habe extreme Schmerzen oder Beschwerden
  - e. **Angst/Niedergeschlagenheit**
    - ... Ich bin nicht ängstlich oder deprimiert
    - ... Ich bin ein wenig ängstlich und deprimiert
    - ... Ich bin mässig ängstlich und deprimiert
    - ... Ich bin sehr ängstlich und deprimiert
    - ... Ich bin extrem ängstlich und deprimiert
- 

### Fragen zum Umgang mit COPD und Ihrer allgemeinen Gesundheit

*Der letzte Abschnitt beinhaltet Aussagen zum Umgang mit COPD. Wir bitten Sie, diese zu bewerten. Dabei geht es primär darum, herauszufinden, wie gut Sie sich über die chronische Lungenerkrankung COPD informiert fühlen.*

Auf einer Skala von sehr einfach bis sehr schwierig, wie einfach ist es Ihrer Meinung nach ...

48. ... Informationen über Therapien für Krankheiten, die Sie betreffen, zu finden?
- ... Sehr einfach
  - ... Ziemlich einfach
  - ... Ziemlich schwierig

... Sehr schwierig

49. ... herauszufinden, wo Sie professionelle Hilfe erhalten, wenn Sie krank sind? (Arzt, Apotheker, Psychologe)

... Sehr einfach

... Ziemlich einfach

... Ziemlich schwierig

... Sehr schwierig

50. ... zu verstehen, was Ihr Arzt Ihnen sagt?

... Sehr einfach

... Ziemlich einfach

... Ziemlich schwierig

... Sehr schwierig

51. ... die Anweisungen Ihres Arztes oder Apothekers zur Einnahme der verschriebenen Medikamente zu verstehen?

... Sehr einfach

... Ziemlich einfach

... Ziemlich schwierig

... Sehr schwierig

52. ... zu beurteilen, wann Sie eine zweite Meinung von einem anderen Arzt einholen sollten?

... Sehr einfach

... Ziemlich einfach

... Ziemlich schwierig

... Sehr schwierig

53. ... mit Hilfe der Informationen, die Ihnen der Arzt gibt, Entscheidungen bezüglich Ihrer Krankheit zu treffen?

... Sehr einfach

... Ziemlich einfach

... Ziemlich schwierig

... Sehr schwierig

54. ... den Anweisungen Ihres Arztes oder Apothekers zu folgen?

... Sehr einfach

... Ziemlich einfach

... Ziemlich schwierig

... Sehr schwierig

55. ... Informationen über Unterstützungsmöglichkeiten bei psychischen Problemen, wie Stress oder Depression, zu finden?

... Sehr einfach

... Ziemlich einfach

... Ziemlich schwierig

... Sehr schwierig

56. ... Gesundheitswarnungen vor Verhaltensweisen wie Rauchen, wenig Bewegung oder übermässiges Trinken zu verstehen?

... Sehr einfach

... Ziemlich einfach

... Ziemlich schwierig

... Sehr schwierig

57. ... zu verstehen, warum Sie Vorsorgeuntersuchungen brauchen? (Krebsfrüherkennung, Blutzuckertest, Blutdruck)

... Sehr einfach

... Ziemlich einfach

... Ziemlich schwierig

... Sehr schwierig

58. ... zu beurteilen, ob Informationen über Gesundheitsrisiken in den Medien vertrauenswürdig sind? (Fernsehen, Internet oder andere Medien)

... Sehr einfach

... Ziemlich einfach

... Ziemlich schwierig

... Sehr schwierig

59. ... aufgrund von Informationen aus den Medien zu entscheiden, wie Sie sich vor Krankheiten schützen können? (Zeitungen, Broschüre, Internet oder andere Medien)

... Sehr einfach

... Ziemlich einfach

... Ziemlich schwierig

... Sehr schwierig

60. ... Informationen über Verhaltensweisen zu finden, die gut für Ihr psychisches Wohlbefinden sind? (Meditation, körperliche Bewegung, Spazieren gehen, Pilates, etc.)

... Sehr einfach

... Ziemlich einfach

... Ziemlich schwierig

... Sehr schwierig

61. ... Gesundheitsratschläge von Familienmitgliedern oder Freunden verstehen?

... Sehr einfach

... Ziemlich einfach

... Ziemlich schwierig

... Sehr schwierig

62. ... Informationen in den Medien darüber, wie Sie Ihren Gesundheitszustand verbessern können, zu verstehen? (Internet, Zeitungen, Zeitschriften)

... Sehr einfach

... Ziemlich einfach

... Ziemlich schwierig

... Sehr schwierig

63. ... zu beurteilen, welche Alltagsgewohnheiten mit Ihrer Gesundheit zusammenhängen? (Trink- und Essgewohnheiten, Bewegung, etc.)

... Sehr einfach

... Ziemlich einfach

... Ziemlich schwierig

... Sehr schwierig

64. Welche Empfehlung würden Sie jemandem geben, der erst kürzlich die Diagnose COPD erhalten hat?

.....  
.....  
.....  
.....  
.....

65. Zurückblickend, was würden Sie im Umgang mit Ihrer COPD aus heutiger Sicht ändern?

.....  
.....  
.....  
.....  
.....

66. Angenommen Sie hätten drei Wünsche im Umgang mit Ihrer COPD frei. Was würden Sie sich wünschen?

.....  
.....  
.....  
.....  
.....

Weitere Anmerkungen

.....

.....  
.....  
.....  
.....

---

Vielen Dank für Ihre Teilnahme!

Mit Ihrer Teilnahme helfen Sie nicht nur der Forschung, sondern tragen auch dazu bei Unterstützungsmöglichkeiten im Umgang mit COPD zu verbessern. Wir danken Ihnen daher sehr, dass Sie sich die Zeit genommen haben, an unserer Umfrage teilzunehmen.


Bei Fragen, Interesse an der Auswertung oder falls Sie an der Verlosung für die 3 Reka-Gutscheine im Wert von je CHF 100 teilnehmen möchten, schreiben Sie gerne eine E-Mail an Anja Bischof (E-Mail: XXX, Tel: XXX).



## Supplementary Material 2: Facebook advertisement

**L** **Lehrstuhl für Management  
im Gesundheitswesen,  
Universität St. Gallen** × ⋮  
Anzeige ·

Leidet einer Ihrer Angehörigen oder Sie selbst  
an COPD und wünschen Sie sich mehr  
Unterstützung im Umgang mit Ihrer Krankheit?  
Dann machen Sie bei unserer Umfrage (DE, IT,  
FR) mit und tragen Sie zur besseren alltäglichen  
Unterstützung von COPD-Betroffenen bei.



ww2.unipark.de  
**Hier geht es zur  
Umfrage** Mehr ansehen

---

Gefällt mir Kommentar Teilen

## Supplementary Material 3: Flyer for recruitment



### Studienteilnehmende gesucht

## Identifikation des Unterstützungsbedarfs von Patient:innen mit COPD

(Chronisch-obstruktive Lungenerkrankung)

#### Teilnehmendenprofil

Wir suchen COPD-betroffene Personen ab 18 Jahren mit deutscher Muttersprache oder guten Deutschkenntnissen.

#### Ziel der Studie

Wir möchten prüfen, ob und welchen Unterstützungsbedarf COPD-Betroffene haben und ob dieser durch bestehende Programme/Angebote genügend abgedeckt wird. Ausgehend von diesen Erkenntnissen soll ein digitaler Gesundheitsassistent entwickelt werden, der die Bedürfnisse der Patient:innen in den Mittelpunkt stellt.

#### Ablauf und Dauer der Studie

Die Studie besteht aus einem Fragebogen, für dessen Beantwortung Sie ungefähr 20 Minuten benötigen (siehe QR-Code und Link). Der Fragebogen beinhaltet Fragen zu Ihrer Lebensqualität, dem Umgang mit Ihrer Erkrankung und einem möglichen Unterstützungsbedarf im Alltag aufgrund Ihrer COPD.



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