

Abstract

Health literacy (HL) is defined as an individual's ability to access, understand and utilise information to make informed decisions. This study aimed to assess HL levels, and explore the relationship between HL and COPD severity.

A cross-sectional study of HL in patients with COPD used the Health Literacy Questionnaire and the MRC breathlessness scale to assess COPD severity.

HLQ domains of 'having sufficient information to manage my health', 'actively managing health', and 'understanding health information' scored most highly. Patients with greatest COPD severity had lower scores in the domain 'having sufficient information to manage my health', but indicated an improved ability to appraise health information.

Patients with increased COPD severity have greater self-reported skills in appraising health information, but report reduced skills in having sufficient information to manage their health. This study highlights the importance of considering HL levels, as this could be a barrier to successful self-management.

Key words

1. Health Literacy
2. COPD
3. Self-management

4. Health Literacy Questionnaire
5. Engaging with health care providers
6. Navigating the health care system

Key points:

1. An individual's health literacy skill impacts on their ability to self-manage and can impact on health related outcomes.
2. Clinicians need to ensure patients have sufficient information to allow them to manage their health, and consider that need is likely to fluctuate with disease severity.
3. The need to support patients in appraisal of health information needs to be a consideration during consultation.
4. Patient's skill in engaging with health care providers should be a consideration of clinicians during consultation.
5. Patient's skills in navigating the health care system should be considered and adequately supported.

1. Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a progressive respiratory condition, characterised by breathlessness and excess sputum production (Wedzicha et al, 2003). Managing COPD places great demands on the affected individual, due to fluctuating progressive respiratory symptoms, overlaid with complex comorbidities (Vogelmeier, 2017; Welch, L 2021) and the reliance on self-management.

Effective self-management requires a range of skills that are vital for an individual to support the day-to-day responsibility of managing their condition, as well as responding to changes or exacerbations. Supporting self-management is a process that should be patient focused, with shared decision making between patient and clinician (Welch et al, 2021). For some individuals the complexity of accessing, understanding and applying new health self-management skills, and changing behaviours constitutes a considerable new workload (May, 2014), and individuals' health literacy skills will impact on their ability to self-manage their long-term condition (Adams, *et al* 2009).

Health literacy (HL) is considered as an individual's ability to access, understand and use information in order to make informed decisions about their health (Batterham et al, 2016; Nutbeam, 2021), however there is a lack of consistency in the definition of in the literature (Larsen et al, 2022). HL is perceived as a skill (which can be improved), a risk factor for poor outcomes, or as a consideration for health professionals when providing care (Nutbeam, 2008). Health literacy incorporates:

being able to understand health information necessary to manage daily health-related tasks; having the communication skills needed for interactions with health care professionals; and being able to navigate health care systems as well as the ability to appraise health information in relation to personal situations in order to exert greater control over their own health outcomes (Nutbeam, 2008).

HL is a major factor in determining how successful patients are at using the medical treatments and support available to them (Kondilis, *et al* 2008), and is thought to be key in decreasing the disease burden of chronic conditions (Heine *et al*, 2021). Low HL levels are correlated with higher levels of morbidity and mortality (Adams *et al*, 2009), and, in COPD, Omachi *et al* (2013) report those with the lowest levels of HL may have a five-times increased risk of visiting the emergency department, and a seven-times increased risk of hospitalisation. In contrast, higher levels of HL are thought to act as a precursor to successful self-management by equipping the individual with the knowledge and skills to manage their own condition and improve their health outcomes (Kondilis *et al*, 2008).

HL is impacted by variables such education level, and psychological wellbeing (Wahl *et al*, 2021). However, HL is also recognised not to be just an individual process, as influences also come from a patient's environment, including their family and support networks, known as collective efficacy (Vassilev *et al* 2019). In addition, external factors such as health care providers and the organisational health care structure influence HL (Betterman *et al*, 2016; Larsen *et al*, 2022). Health inequalities influenced by socioeconomic status also play a role in determining health outcomes (Gershon *et al*, 2012; Li *et al*, 2022). As a result, understanding HL levels in various

populations may be key to developing supportive strategies (Friis *et al*, 2016).

Health literacy is particularly relevant for COPD populations. Studies that have explored HL in participants with COPD suggest HL may be lower in this group compared to other non-chronic disease populations, such as people with diabetes or heart failure. Puente-Maestu *et al*. (2016) support this with 59% of their COPD sample having inadequate HL levels and a reduced understanding of their disease. HL in COPD is associated with poor health outcomes, including; respiratory specific health outcomes and quality of life outcomes (Stellefson *et al*, 2019). Furthermore, patients report increased difficulty in completing their activities of daily living, along with increased levels of dependency and failure to respond to exacerbations, can resulting in more hospital admissions.

Whilst the above studies make important contributions to understanding the impact of HL for people living with COPD, several gaps remain. Firstly, the outcome measures used to measure HL in COPD (Puente-Maestu, 2016; Omachi, 2013) are predominately concerned with reading and comprehension, functional levels of HL and, consequently, may not adequately measure the breadth of the skills that contribute towards HL (Nutbeam, 2008). Secondly, research in a local UK sample is needed due to differing health care systems and populations between countries, and it cannot be assumed that previous findings are generalisable to the UK population. As a result, the aim of this research is to investigate HL levels across a UK based COPD population to address the HL gap in the research. This is key as with more self-management tools becoming digitalised, understanding HL prior to digital literacy enables informed development of digital media in people with COPD.

2. Methods

This study aimed to describe the health literacy levels of people with COPD in a UK population and explore the relationship between HL levels and COPD severity. The study objectives were to:

- I. Describe the composite HL level of participants with COPD using the Health Literacy Questionnaire (HLQ) (Osborne *et al*, 2013).
- II. Identify domains in which participants have relatively higher and lower levels of HL using the HLQ.
- III. Describe the relationship between the composite scores of HL level, using the HLQ and COPD severity using the MRC breathlessness scale (Bestall *et al*, 1999).

Design and sampling

A cross-sectional, observational design was used to measure HL using the HLQ and COPD severity using the MRC breathlessness scale. This study design was selected as it allowed for data to be collection at a one-off time point, across a large sample. This is appropriate as HL is deemed to be a relatively stable skill (Nutbeam, 2008), and by collecting data at one-off time point it reduced risk of loss to follow up (Mann, 2003). The HLQ was selected as it considers the breadth of skills that make up HL (Osborne *et al*, 2013), rather than focusing solely on reading and comprehension.

Ethical approval for the study was granted by the North West – Liverpool East Research Ethics Committee. Participants were eligible to take part in the study if

they were 18 years or older and reported to have a diagnosis of COPD. There were no restrictions on participants' disease status or level of health. Participants were excluded if they were unable to give informed consent, unable to read and understand English, as no funds for a translator were available for this study, or identified as unsuitable due to factors like a cognitive impairment, that would restrict their ability to give informed consent, as decided by one of the patient's direct care team.

The desired sample size for this study was calculated by using the results of Friis et al's (2016) paper, we did so by using their estimates of outcome variability, otherwise known as the standard deviation, for two of the domains of the HLQ used in this paper. These estimates have been used to ensure we target our desired level of precision, 95% confidence intervals, to ensure our sample is a good reflection of the population. Based on these figures, a sample of 80 allows for this level of accuracy.

Study setting and recruitment strategy

Recruitment ran from December 2017 to June 2018 via one of three routes: 1) NHS outpatient clinics, 2) NHS pulmonary rehabilitation (PR) or PR maintenance and 3) Breathe Easy groups, in localised region of the UK. This approach was chosen to maximise ability to meet the sample size requirement.

When recruiting in NHS clinics, the direct care team screened and invited eligible patients to the study. For PR and Breathe Easy groups the researcher attended a group session and gave a summary of the study to group attendees. Interested

patients were given a research pack, which included a stamped addressed envelope in which to return their completed questionnaire. Return of the questionnaire was taken as implied consent.

Data collection materials

Data was collected using three questionnaires:

1. Participant demographics questionnaire: included age, sex, ethnicity, time since (COPD) diagnosis in years, and number of comorbidities. This allowed this sample to be compared to the UK COPD population (Snell *et al*, 2016).
2. The Medical Research Council (MRC) breathlessness scale (Bestall *et al*, 1999), as shown in Table 1, was used to measure the level of subjective breathlessness, as an indication of COPD severity, allowing comparisons between HL level and COPD symptoms.
3. The Health Literacy Questionnaire (HLQ), was used to measure HL (Osborne *et al*, 2013). This 44-item tool was selected as it covered all of the key areas of HL (Nutbeam, 2008). The HLQ includes nine domains of HL as shown in Table

The Medical Research Council (MRC) breathlessness scale	
Grade	Description
1	Not troubled with breathlessness except with strenuous exercise
2	Troubled by shortness of breath when hurrying on the level or walking up a slight hill
3	Walks slower than people of the same age on the level because of breathlessness or has to stop when walking at own pace on the level
4	Stops for breath after walking about 100 yards (90m) or after a few minutes on the level
5	Too breathless to leave the house or breathless when dressing or undressing

Table 1. The MRC breathlessness scale

2.

The Health Literacy Questionnaire	
Low level of domain	High level of domain
Feeling understood and supported by healthcare providers (HCP)	
Unable to engage with doctors and other healthcare providers. Do not have a regular healthcare provider and/or have difficulty trusting healthcare providers as a source of information and/or advice	Has an established relationship with at least one healthcare provider who knows them well and who they trust to provide useful advice and information and to assist them to understand information and make decisions about their health.
Having sufficient information to manage my health (HSI)	
Feels that there are many gaps in their knowledge and that they do not have the information they need to live with and manage their health concerns.	Feels confident that they have all the information that they need to live with and manage their condition and to make decisions.
Actively managing my health (AMH)	
Do not see their health as their responsibility, they are not engaged in their healthcare and regard healthcare as something that is done to them.	Recognise the importance and are able to take responsibility for their own health. They proactively engage in their own care and make their own decisions about their health. They make health a priority.
Social support for health (SS)	
Completely alone and unsupported for health	A person's social system provides them with all the support they want or need for health.
Appraisal of Health information (CA)	
No matter how hard they try, they cannot understand most health information and get confused when there is conflicting information.	Able to identify good information and reliable sources of information. They can resolve conflicting information by themselves or with help from others.
Ability to actively engage with healthcare providers (AE)	
Are passive in their approach to healthcare. They accept information without question. Unable to ask questions to get information or to clarify what they do not understand. They accept what is offered without seeking to ensure that it meets their needs. Feel unable to share concerns. They do not have a sense of agency in interactions with providers.	Is proactive about their health and feels in control in relationships with healthcare providers. Is able to seek advice from additional healthcare providers when necessary. They keep going until they get what they want. Empowered.
Navigating the healthcare system (NHS)	
Unable to advocate on their own behalf and unable to find someone who can help them use the healthcare system to address their health needs. Do not look beyond obvious resources and have a limited understanding of what is available and what they are entitled to.	Able to find out about services and supports so they get all their needs met. Able to advocate on their own behalf at the system and service level.
Ability to find good health information (FHI)	
Cannot access health information when required. Is dependent on others to offer information.	Is an 'information explorer'. Actively uses a diverse range of sources to find information and is up to date.
Understand health information enough to know what to do (UHI)	
Has problems understanding any written health information or instructions about treatments or medications. Unable to read or write well enough to complete medical forms.	Is able to understand all written information (including numerical information) in relation to their health and able to write appropriately on forms where required.

Table 2.

The HLQ uses a psychometric scale to underpin the domains, with each question increasing in difficulty within the same domain, allowing us to measure the breadth and depth of each area of HL. This ensures the scale is sensitive enough to detect small changes, regardless of the participant's level of HL (Bloom, 1956). Additionally, the scale was shown to have good reliability and validity (Osborne, 2013; Raykov, 1997).

Analysis

Following manual data entry onto excel, the team statistician checked 33% of the participants' data for potential errors. Data was analysed in SPSS v24 (IBM Corp). Histograms were used to guide choice of summary statistics. Mean and standard deviation were used for continuous demographics. Number of comorbidities is presented as median and quartiles. Categorical data were displayed using the number and percentage of the total sample for each category. HLQ results are presented as means, with corresponding 95% confidence intervals, and standard deviations for each of the nine domains.

Following visual assessment of the relationship between MRC and HLQ domains, Spearman's correlations were calculated between each HLQ domain and the MRC score to measure the strength and direction of the relationship, which are presented with 95% confidence intervals.

Where participants ticked multiple boxes on the MRC scale in response to which statement best described how breathlessness affected their activities, the MRC score recorded was taken from the highest score participants selected indicating the

worst degree of breathlessness they reported. This decision is supported by the inherent progressive nature of the scale, requiring the participant to experience symptoms from all the previous boxes. Missing data on the HLQ was managed by following the HLQ scoring advice provided by the developers of the HLQ (Osborne *et al*, 2013).

3. Results

Of the 130 questionnaire packs distributed, 61 participants returning the questionnaires, a return rate of 47%. The was split was 29 from clinics (48%), 21 from Breathe Easy support groups (34%), and 11 from PR classes/maintenance groups (18%). This study recruited roughly two thirds of the participants from the NHS clinics and PR/maintenance groups in order to reduce a potential for bias of attending a support group, which has the potential to favour those of higher HL.

Participant demographics

Participant demographics can be found in Table 3.

Table 3: Participant demographics

Demographic	N (%)
Sex (F/M)	27 (44%) / 34 (56%)
Ethnicity	
White British	60 (98%)
Missing	1 (2%)
	Mean (SD)
Age (years)	70 (7.9)
Time since diagnosis (COPD; years)	8.1 (6.2)
MRC	3.2 (1.1)
	Median (quartiles)
Number of comorbidities	2.0 (1, 3)

Health Literacy Questionnaire

Mean scores and confidence intervals for each domain of the HLQ are shown in Table 4. The means scores for each domain indicate a patients self-reported level of confidence in each skill, with higher scores indicating higher levels of confidence in that skill. The results of each domain are also displayed in two box and whisker plots, which are a way of representing the distribution of the data, including the median, mean and interquartile ranges. The whiskers demonstrate the outliers. Part one of the HLQ is shown in Figure 1 and part 2 is shown in Figure 2.

Scores were similar across all of the domains in part one of the questionnaire, with the exception of 'appraisal of health information' (mean: 2.6, 95% Confidence Interval: 2.5, 2.7), which was lower. In part two, the ability to 'understand health information well enough' scored noticeably higher (mean 3.8, 95% Confidence Interval: 3.6, 4.0) and two, 'navigating the health care system' scored the lowest (mean 3.2, 95% CI: 3.0, 3.4).

Table 4: HLQ domain scores

HLQ Scale	Number of people	Mean score (SD)	95% CI for mean
Part 1 (Scale 1-4)			
Feeling understood and supported by health care providers	61	2.8 (0.7)	2.7 to 3.0
Having sufficient information to manage my health	61	2.9 (0.5)	2.8 to 3.1
Actively managing my health	61	2.9 (0.5)	2.8 to 3.1
Social support for health	61	2.9 (0.6)	2.7 to 3.0
Appraisal of health information	61	2.6 (0.5)	2.5 to 2.7
Part 2 (Scale 1-5)			
Ability to actively engage with healthcare providers	61	3.4 (1.0)	3.2 to 3.6
Navigating the healthcare system	61	3.2 (0.8)	3.0 to 3.4
Ability to find good health information	61	3.4 (0.8)	3.2 to 3.6
Understand health information well enough to know what to do	61	3.8 (0.7)	3.6 to 4.0

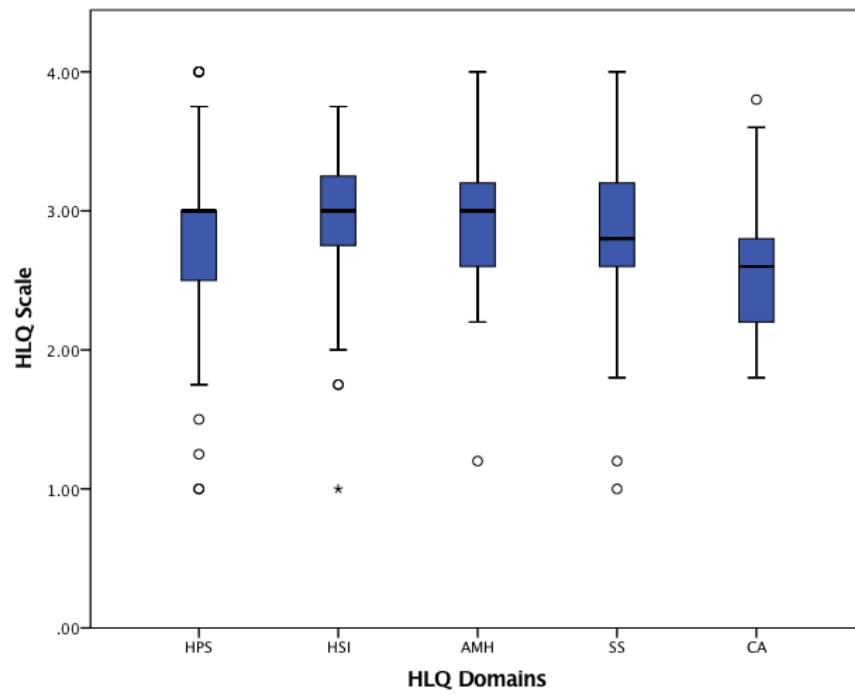


Figure 1. Part 1 HLQ Domain Means

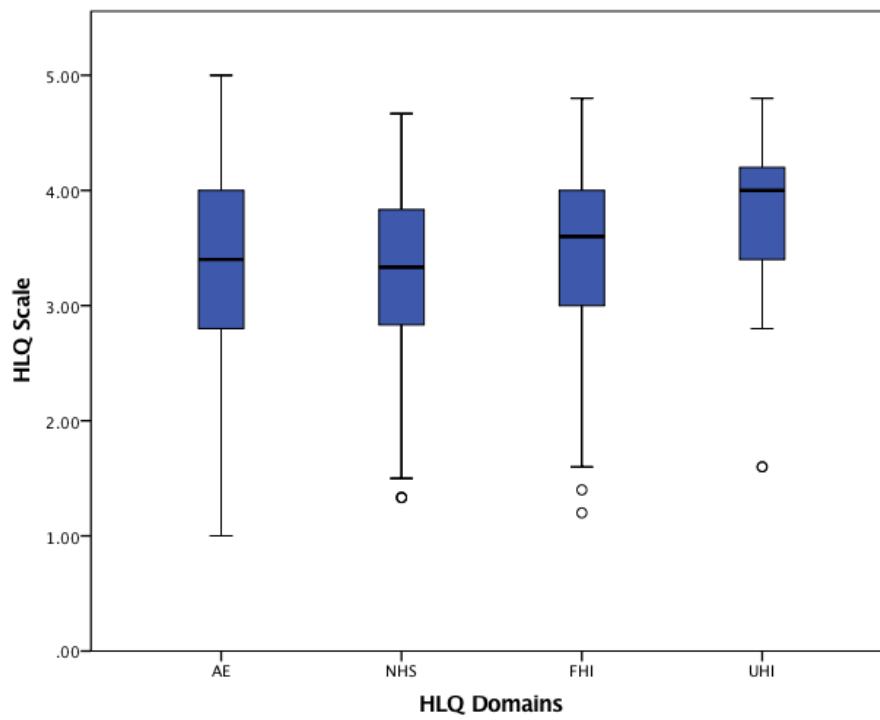


Figure 2. Part 2 HLQ Domain Means

HLQ Domain Abbreviations

HPS	Feeling understood and supported by healthcare providers
HSI	Having sufficient information to manage health
AMH	Actively managing my health
SS	Social support for health
CA	Appraisal of health information
AE	Ability to actively engage with health care providers
NHS	Navigating the health care system
FHI	Ability to find good health information
UHI	Understanding health information well enough to know what to do

Health Literacy Questionnaire and Chronic Obstructive Pulmonary Disease severity

Table 5 displays the results of a Spearman's bivariate analysis, a Spearman's bivariate analysis is designed to measure the strength of a relationship and between two variables and the direction of the relationship. Table 5 displays the relationship and direction of the relationship the mean of each of nine HLQ domains, which higher scores indicating greater confidence in that skill, and the MRC breathlessness scale, of which higher scores indicate greater breathlessness. Two of the nine domains displayed a statistically significant correlation with MRC. The first shows a negative correlation for 'having sufficient information to manage my health' and MRC score ($r = -0.27$, 95% CI $[-0.50$ to $-0.01]$, $p = 0.04$), demonstrating that people with more severe breathlessness reported not having enough health information available to them. Secondly, a statistically significant positive correlation was seen between MRC score and 'Appraisal of health information' ($r = 0.26$, $[0.01$ to $0.48]$, $p = 0.04$), highlighting that people with more severe breathlessness report greater skill in appraising health information. The other domains in the HLQ did not show statistically significant correlations with MRC.

Table 5: correlations between HLQ domains and MRC breathlessness

Domain	Spearman's Correlation	95% CI	p-value
Feeling understood and supported by health care providers	-0.11	-0.36 to 0.15	0.39
Having sufficient information to manage my health	-0.27	-0.50 to -0.01	0.04
Actively managing my health	0.08	-0.17 to 0.31	0.55
Social support for health	-0.04	-0.30 to 0.21	0.77
Appraisal of health information	0.26	0.01 to 0.48	0.04
Ability to actively engage with healthcare providers	-0.07	-0.31 to 0.16	0.57
Navigating the healthcare system	-0.05	-0.29 to 0.19	0.68
Ability to find good health information	-0.08	-0.31 to 0.14	0.57
Understand health information well enough to know what to do	0.00	-0.25 to 0.25	0.98

4. Discussion

This is the first study to assess HL in a UK based COPD population using the HLQ.

The higher percentage of males in the sample reflects that of the wider UK COPD population (Snell *et al*, 2016). COPD is a condition strongly linked to increased smoking prevalence, and occupational exposure (Hegewald, 2007), which are both more prevalent in demographics with lower socioeconomic status (Lindström, 2014). Throughout the literature there is strong evidence to support that low socioeconomic status, including low educational attainment, is linked with poor health outcomes (Eisner *et al*, 2009; Gershon *et al*, 2012). As a result, we need to consider that the increased prevalence of low socioeconomic status in a COPD population might explain some of the differences seen in HL with the general public. This highlights a potential area for consideration for those designing or delivering health care services.

The aim of the study was to explore HL levels in our UK based COPD population, and by looking at the individual domains of the HLQ we were able to identify areas in which our population felt they were more and less confident in their ability, which included domains describing patients' own actions or abilities. These findings contrast with research in the general population, suggests that these groups score highest on social interaction and communication type domains (Jessup, 2017; Hawkins, 2017). This supports that HL levels across the HLQ domains may differ between people with COPD and a non-COPD population (Beauchamp, 2015; Chew, 2004).

This is supported by Friis et al's (2016), data, which indicated that people with chronic conditions might score lower for the 'engaging with HCPs' domain compared to those in the general public. This could be a reflection on the wider health service, and the organisational HL not being designed to support patients with chronic conditions, with many services being reactive rather than proactive to changes in a patient's condition. This has been recognised in the NHS Long Term plan (NHS 2023), including financial commitments to enable the realisation of proactive care. However, in terms of HL, clinicians also report that patients with COPD have difficulties engaging with them (Hawkins *et al*, 2017). There are several explanations for why people with COPD may score lower in these domains. One proposition that has been discussed in the literature (Hawkins *et al*, 2017) may be a lack of skill in communicating with HCPs, and this might reflect difficulties in communication and confidence in complex conversations. A difficult or misinterpreted interaction with a HCP not only is unhelpful, but it might be damaging in future care or treatment decisions, as research suggests that rushed interactions led to people with COPD

being less invested in their own self-care (Welch et al, 2021). Hawkins et al's (2017) found that clinicians in this study reported feeling that patients do not ask the 'right' questions in consultations, as they believed they were not always able to identify gaps in their knowledge. However, this suggests that the 'right' questions are those considered so by the clinician, it privileges health professional concerns over those of patients. In addition, the lack of social support reportedly experienced by patients with COPD (Stellefson et al, 2017), could influence how they communicate and engage with HCPs and this may subsequently be reflected in their HLQ scores for social/interactive domains. Welch et al (2021) support an approach focused more towards personal and peer acquired knowledge when considering effective COPD self-management, as research supports that patients self-management strategies form more spontaneously, in response to symptoms (Apps, et al 2014), than from formal education from their HCP.

Our study also highlights areas of the HLQ that are relatively lower amongst our COPD participants, including 'appraisal of health information' and 'navigating the health care system'. The low-scoring 'appraisal of health information' domain was in keeping with research in a non-COPD specific population (Beauchamp, 2015; Jessup, 2017). However, our results differed with respect to the 'ability to navigate the health care system', which was a low-scoring area for our COPD population. This may be an important finding as an inability to navigate the HCS may be associated with sub-optimal use of care and/or self-management, especially as health care services become increasingly virtual in a post pandemic health care system. Further research to understand how people with COPD navigate HCS would be valuable,

and including patients in co-design of future interventions would be key to improve services (Roberts et al, 2008).

The secondary findings of our study show a relationship between two of the HLQ domains and COPD severity. The first relationship highlights that participants with more severe COPD reported lower scores for 'having sufficient information to manage health'. This may be due to patients with less severe COPD requiring less information to manage their condition. However, it may also be the case low HL has led to lower ability to manage health, consequently leading to poorer health outcomes.

The second relationship indicated that appraisal skills also improved with increased COPD severity. Our findings resonate with Stellefson et al (2017) study into e-health literacy); they also found that people with more severe COPD scored higher on a scale on appraising information than those with less severe COPD. Worsening COPD status may drive the need to improve appraisal skills. Alternatively, COPD status is also likely to be an indicator of length of time since diagnosis; as a result, any improvements in appraisal could be as a result of having had longer to develop the skills. It should also be considered in the context of patient centred strategies to improve and promote independence (Welch et al, 2021)

Whilst this study provides insight into an under researched group, it should be noted that this study has several limitations. Firstly, whilst the HLQ provides a more comprehensive assessment of health literacy, the clinically significant ranges have not yet been defined. As such, it is not possible to distinguish between those with

high, adequate or low HL levels of HL, unlike some other albeit simpler HL measures (Chew, 2004; Murphy, 1993). To improve this in future studies, a summative measure that categorises HL in these terms could be used alongside the HLQ. Research by Wahl et al (2021) shows the impact of psychological wellbeing, and needing to consider this when determining HL needs of a COPD population, considerations need to be made for this, and other confounding variables not measured in the study, as shown in this paper. Another limitation was our failure to reach the target sample size of n=80. However, we were still able to achieve a level of precision very close to the planned figure. Another limitation is the self-reported nature of the MRC, which although is a reflection of patient reported breathlessness, does not necessarily correlate to disease severity. Finally, whilst our sample provided a fair reflection of the UK COPD population in terms of age and sex, it was homogenous in relation to ethnicity, which may reduce the generalisability of the study. Our need for patients to be able to read and understand written English due to a lack of translation services might have contributed towards this.

5. Conclusion

Our study suggests that on a population level, people with COPD may find appraising health information and navigating the HCS to be the most challenging domains. Further research is needed to understand what aspects specifically present challenges in these areas; this will inform the design of future interventions and/or services. Our finding that as disease severity increases, perception of having sufficient information decreases, perhaps highlights the need for research to understand the changing informational needs of people with COPD throughout the

course of their condition. These findings are specifically relevant for health care professionals who work with patients with COPD and should be considered in relation to information provision, patient engagement and service design.

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