THE ROLE OF HEALTH LITERACY IN CHRONIC RESPIRATORY DISEASE MANAGEMENT

by

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Abstract

Background: Health literacy (HL) is defined as the ability to access, understand, evaluate, communicate, and use health information to make informed health decisions. Studies have reported a relationship between low HL and less health-related knowledge, poorer skills in taking medication, and treatment non-adherence. Despite this, measurement of HL (in particular to the abovementioned domains) is still in its infancy and the impact of HL on self-management (via a key informant lens) has yet to be studied.

Objectives: The main aim in this thesis was to incorporate both sides of the HL equation (patients and key informants) into investigating the role of HL in chronic respiratory disease management. This led to two objectives: 1) To identify HL tools used in asthma and/or chronic obstructive pulmonary disease (COPD) management and examine their characteristics; and 2) To assess key informants' perspectives re barriers to asthma/COPD self-management and the solutions to address such challenges.

Methods: A systematic review was undertaken to review the literature on HL tools that assessed any of the five domains on asthma/COPD patients. Following this, a qualitative study was conducted with national and international key informants (e.g., health care professionals (HCPs), researchers, and policymakers) who were involved in the care of asthma/COPD patients to determine perceived patient barriers to competent self-management and the possible solutions to overcome these barriers.

Results: The review identified 65 tools with a majority assessing 'understanding' and a minority on 'communication'. Only two tools assessed all five domains and less than half had been validated. Thematic analysis of the 45 interviews resulted in seven barriers surrounding the themes of time, information overload, and jargon and six solutions focusing on tailored education, better communication, and building relationships.

Conclusions: Self-management is a combined effort achieved only through the engagement of patients, HCPs, and the system. Both studies showed shortcomings in the 'communication' domain, possibly due to the complex phenomenon of communication requiring at least two individuals in the process. These findings suggest that HL researchers and health care programs should recommend new strategies for chronic respiratory disease management with a specific emphasis on the concept of 'communication'.

Lay Summary

A patient's level of health literacy (HL), defined as the ability to: (1) access, (2) understand, (3) evaluate, (4) communicate, and (5) use health information, is important to properly self-manage chronic condition(s). Existing asthma and/or chronic obstructive pulmonary disease (COPD) measurement tools are not complete in terms of assessing all five domains of HL and are primarily focused on 'understanding' while lacking information on a patient's ability to 'communicate' health information. Health care professionals (HCPs) also play an important part in successful self-management. HCPs, researchers, and policymakers acknowledge the limitations in their communication with asthma/COPD patients and suggest actions that they can take to combat these barriers such as tailoring health education to the patient's HL level and building trustful relationships.

Preface

All chapters in this thesis are based on work conducted in the UBC's Division of Respiratory Medicine, Department of Medicine under the supervision of Drs. J. Mark FitzGerald and Iraj Poureslami as part of the Canadian Institutes of Health Research (CIHR) funded 'Development and validation of Canadian health literacy measurement tool for chronic disease management' grant. I was responsible for all procedures of chapters 2 and 3 with the exception of performing the systematic review search and acquiring ethics approval. My supervisor, Dr. J. Mark FitzGerald and MSc committee members, Drs. Iraj Poureslami, Laura Nimmon, and Iris van der Heide provided me with their comments and advice throughout the thesis work.

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Published abstract

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Ethics approval was obtained for chapter 3 from the UBC's Behavioural Research Ethics Board (ethics certificate #H15-01954-A004).

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List of Abbreviations

ABC	Asthma Behaviour Change
АНР	Allied Health Professionals
ANQ	Asthma Numeracy Questionnaire
AP	Advisory Panel
ASMQ	Asthma Self-Management Questionnaire
ATAQ	Asthma Therapy Assessment Questionnaire
ВТ	Batalla Test
BCKQ	Bristol COPD Knowledge Questionnaire
CCHL	Calgary Charter on Health Literacy
CEPHL	Canadian Expert Panel on Health Literacy
CIHR	Canadian Institutes of Health Research
COPD	Chronic Obstructive Pulmonary Disease
COPD-Q	Chronic Obstructive Pulmonary Disease Knowledge Questionnaire
COPD-SMI	Chronic Obstructive Pulmonary Disease Self-Management Interview
CPR	Cardiopulmonary Resuscitation
CQ	12-item Consumer Asthma Knowledge Questionnaire
ED	Emergency Department
НСР	Health Care Professional
HL	Health Literacy
HLS-EU-Q	European Health Literacy Survey Questionnaire
IQ	Intelligence Quotient

КАР	Knowledge, Attitude, and Practice
KASE-AQ	Knowledge, Attitude, and Self-Efficacy Asthma Questionnaire
LINQ	Lung Information Needs Questionnaire
MARS	Medication Adherence Report Scale
MDI	Metered-Dose Inhaler
MeSH	Medical Subject Headings
MISS	Medical Interview Satisfaction Scale
NVS	Newest Vital Sign
РАСТ	Patient Asthma Concerns Tool
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
QoC	Quality of Communication Questionnaire
REALISE	REcognise Asthma and LInk to Symptoms and Experience
REALM	Rapid Estimate of Adult Literacy in Medicine
RCT	Randomized Control Trial
SMOG	Simple Measure of Gobbledygook
SMS	Short Message Service
SOLDQ	Seattle Obstructive Lung Disease Questionnaire
TOFHLA	Test of Functional Health Literacy in Adults
TV	TeleVision
UBC	University of British Columbia
UCOPD	Understanding COPD Questionnaire

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Dedication

To my parents and brother

Chapter 1: Introduction

1.1 Background

1.1.1 Asthma and chronic obstructive pulmonary disease (COPD) self-management

The incidence and prevalence rates of chronic diseases are increasing worldwide due to an aging population and changes in lifestyles [1,2]. Asthma and chronic obstructive pulmonary disease (COPD) are two chronic respiratory diseases that have a significant global burden [3-5]. It has been estimated that over three million Canadians are affected by asthma [6] with prevalence rates increasing over the last 20 years [6-9]. With the current and increasing incidence and prevalence, asthma also creates substantial societal burden with high numbers of emergency department (ED) visits, hospitalizations, and prescriptions filled, all negatively affecting health-related quality of life [6,10,11]. COPD is currently the fourth leading cause of death in the world [12,13] and is the leading cause of medical hospitalizations in Canada [14]. In the province of British Columbia, Canada, the total number of COPD cases is projected to grow by more than 150% between 2010 and 2030 as a result of population aging. COPD-related hospitalization has also been predicted to increase by 210% during this period [15].

Self-management, described as the tasks and actions an individual living with a chronic disease must perform in order to fully gain control of his or her condition, is crucial to prevent the worsening of asthma and COPD, ultimately minimizing the unnecessary use of care and promoting better health-related quality of life for those affected [16-19]. Such tasks include being able to properly recognize and monitor symptoms, correctly use and adhere to medical regimens and instructions, and successfully cope and deal with lifestyle changes or other factors associated in living with the chronic disease [19-22]. To be able to adequately self-manage a chronic condition requires the ability and process of demonstrating sufficient knowledge, skills, confidence, and judgment to make informed decisions to live well and overcome barriers and obstacles faced in disease management [20-21]. Optimal self-management includes goal setting, educational interventions, active involvement in decision making, and collaboration between the patient, their family, and the health care professionals (HCPs) involved in the care of the disease [20,22].

1.1.2 Association between health literacy (HL) and self-management

The term health literacy (HL) was first used in 1974 in a discussion panel regarding health education as a social policy issue affecting burden on the health care system [23]. Since then, it has been discussed within the context of literacy and health [24] but as the concept evolved, more definitions were suggested by different health researchers and organizations [24,25]. Most commonly, HL is labeled as a spectrum of knowledge and skills a person must require to effectively obtain, process, and understand health information [25-28]. In 2009, the Calgary Charter on Health Literacy (CCHL) [26] conceptualized a model inclusive of five core domains, defining HL as a person's ability to: (1) access, (2) understand, (3) evaluate, (4) communicate, and (5) use health information to make informed decisions for one's health. In addition to broadening the scope of patient competency in managing their chronic disease, the CCHL definition also underscores the importance of health care professionals' HL performance in their delivery of information, and furthers the inclusion of these concepts in the structure of the health care system [29]. This wide-ranging definition, with relevance to many key players in the health care interaction (e.g., patients, clinicians, nurses, and other allied health professionals, etc.), established the CCHL definition as the reference standard. The concept of 'numeracy' has also been proposed as an important component of HL, referring to the capability of individuals to interpret and apply numerical health information needed to make effective health decisions [30].

In 2011, Berkman et al. [31] updated the results of their 2004 systematic review [32] on HL and health outcomes and identified that low HL was associated with severe adverse health outcomes (e.g., poorer overall health status and higher mortality rates), greater use of health care services such as increased hospitalizations, greater use of emergency care, and a lower ability to interpret prescription labels and health messages. More specifically, the authors found that low HL was related to poorer skills in taking medications and less health-related knowledge. The relationship between numeracy and health outcomes was inconclusive due to limited studies and inconsistent results. Another systematic review conducted by Easton et al. [33] on low HL and health in working age adults reported a relationship between low HL and access to and use of health services (e.g., less appropriate use of services) as well as poorer medication adherence.

In a cross-sectional study by Williams et al. [34] in Torrance, California, almost half of the patients with hypertension or diabetes were found to have inadequate HL and those patients had significantly less knowledge of their disease and essential self-management skills. In terms of asthma, Gazmararian et al. [35] conducted a study with Medicare enrollees aged 65 years or older who had at least one chronic disease (asthma, diabetes, congestive heart failure, or hypertension) and showed that asthma patients with inadequate HL were significantly less likely to correctly answer 40% of asthma-related questions.

1.2 Outline of this thesis

In this thesis, I initially focused in chapter 1 on observing the role of HL in chronic respiratory disease management. This thesis aimed to first review the current literature on the measurement of HL in relation to asthma/COPD management (tools only assessing the patient's ability) and then provide insights into the barriers and solutions of self-management via the perspectives of key informants who are involved in

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the care of patients with asthma and/or COPD (concentrating on the other key players in selfmanagement). By incorporating both the patients' ability and viewpoints of key informants, the information obtained on HL was comprehensive and inclusive of the role of the patient and the health care system in regard to self-management. To determine the existence of HL measurement tools for asthma/COPD management and its deficiencies (e.g., whether present tools are comprehensive of all five HL domains and/or have been validated), a systematic review was undertaken in chapter 2. Following in chapter 3, a qualitative study was conducted to identify the perspectives of HCPs (e.g., clinicians, respiratory educators, pharmacists, nurses, etc.), researchers, and policymakers on the perceived barriers an asthma and/or COPD patient may be faced with and the possible solutions that they suggest to overcome and address such challenges. The findings in this chapter were based on data that were obtained as part of a larger study aiming to develop and validate a Canadian HL measurement tool for chronic disease management. Finally, in chapter 4, I summarized and discussed the findings of the two studies presented in this dissertation. I also highlighted clinical and policy implications as well as identify potential research actions that can be done to build on the work from this thesis.

Chapter 2: Airway diseases and health literacy (HL) measurement tools: a systematic review to inform respiratory research and practice

2.1 Introduction

The Calgary Charter on Health Literacy (CCHL) [26] defines health literacy (HL) as the ability to: (1) access, (2) understand, (3) evaluate, (4) communicate, and (5) use health information to make informed decisions for one's health. 'Numeracy' is also an important component of HL and is referred to as "an individual's capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical, and probabilistic health information needed to make effective health decisions" [30]. Research on HL has grown tremendously in the past two decades but despite the importance of each HL domain being well-established individually [29,36] and the CCHL's 5-domain model being endorsed and approved by different HL researchers and experts [37,38], measurement of HL is still in its infancy and significant limitations (e.g., focusing on only one or two aspects of HL, such as word comprehension or reading ability [39,40]) remains [38-41]. The most often used HL research tools are the Test of Functional Health Literacy in Adults (TOFHLA) [42], the Rapid Estimate of Adult Literacy in Medicine (REALM) [43], and the Newest Vital Sign (NVS) [44,45]. These tools largely measure reading ability (e.g., word pronunciation), print literacy, or numeracy [43] and fail to address the other elements of the 5-domain model, for example, the ability to critically evaluate and apply such information in day-to-day life [41].

The limitations with existing tools prevent researchers and clinicians from effectively assessing and measuring HL [36-40,46]. More specifically, existing tools do not adequately capture the data necessary to understand how HL, as a complex concept, is a determinant of health outcomes [38,47] and which domains play a crucial role in this regard. Therefore, existing tools are thus inadequate in identifying

specific areas of improvement needed within the domains [36,39,47,48]. Another limitation of current tools is the challenge of differentiating between 'health literacy' and 'basic literacy', in that, the majority of these tools are not disease-specific measurement tools and often lack relevance to a specific chronic condition [39,49-51]. The limited scope of existing tools prohibits researchers and clinicians from identifying possible mechanisms and/or interventions needed to improve disease management (e.g., knowledge enhancement, skill improvement, and behaviour modification strategies) [52]. Ideally, there needs to be a single comprehensive measurement tool assessing all five domains of HL as well as numeracy in order to adequately assess HL, identify the specific gaps or areas of weaknesses between each of the domains, and determine where targeted interventions may be needed [38,46,47].

There are only a few reviews conducted on the deficiencies of HL measurement tools. For instance, in 2006, Kwan et al. [51] performed a comprehensive literature review to identify the gaps in existing HL measurement tools. Properties for each tool were compared and the strengths and limitations were clearly identified with the objective of developing a Canadian HL measurement tool to be used among older adults. The authors developed a conceptual framework for HL in addition to an English version of the tool and tested it with an older population group (65 years of age or older). Although this was a promising accomplishment, their tool was not disease-specific and was not validated by the same team or by other researchers. In 2011, a critical appraisal of HL by Jordan et al. [39] found wide variations of constructs and content across HL tools, and none of them appeared to fully measure a person's ability to seek, understand, and use health information. The content of these tools were mainly focused on reading comprehension and numeracy, scoring categories were poorly defined, and very few tools had been assessed for reliability. More recently, in 2014, Haun et al. [53] undertook a systematic review of 51 HL measurement tools and showed that only a minority of tools assessed all of the defined dimensions of HL.

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The review concluded that comprehensive validated measurement tools for diverse populations are needed.

To our knowledge, there is currently no evidence in the literature on HL measurement tools containing the CCHL's 5-domain model and numeracy as related to asthma and chronic obstructive pulmonary disease (COPD) management. During the 2013 'Creating a Knowledge Hub in Health Literacy and Chronic Disease Management International Research Roundtable' held at the University of British Columbia (UBC), Vancouver, Canada, a call for action regarding the development of a globally comparable and reliable population-based HL measurement tool for chronic disease management was stressed by participating scholars, clinicians, and policymakers [54]. To build on this call for action and further explore existing HL tools related to asthma and COPD management, I conducted a systematic review looking at tools that measured any of the five HL domains as well as numeracy domain using the following research questions:

- How well do the items in the tools map onto the domains?
 - To what extent are the domains covered in the existing tools?
- How many of the tools have been validated and out of the validated tools how well do they
 address key components (e.g., complete assessment of the five HL domains, a conceptual
 model/framework behind item development, and detailed descriptions of scoring and
 validation processes such as psychometric properties)?

My hypothesis was that a majority of the identified tools will be heavily focused on the 'understand' domain as it is assumed that assessment of patient 'knowledge' is an easy and attractive concept for both researchers and health care professionals (HCPs) in comparison to assessing the other HL domains.

In this review, I report on important characteristics of identified tools such as the distribution of HL domains, underlying content, number of items, types of response options, scoring, readability, administration, as well as strengths and weaknesses. In addition, key components available for validated tools were reviewed and evaluated based on a checklist that was developed exclusively in this study.

2.2 Methods

2.2.1 Study inclusion criteria

Development, use, and/or validation studies such as cross-sectional surveys, cohort studies, and randomized control trials (RCTs) of psychometric tools pertaining to any of the five HL domains and numeracy will be included. Table 2.1 includes the definitions for each of the domains. Studies needed to focus on adult asthma or COPD patients as diagnosed by a physician or respiratory therapist. Measurement tools can contain various formats such as open-ended, closed-ended (e.g., true/false, multiple choice), scenario/passage, puzzle or pictorial type items either self-administered, assisted through an interviewer, or electronic based. The term 'health literacy' was first used in 1974 during a discussion on health education as a policy issue affecting the health system [23]; therefore, the review will include the years 1974 to 2016. Only English language papers were included.

Qualitative studies or studies with measurement tools assessing the HL of health care providers, caregivers, or the general population were excluded. Consensus was also used to exclude inhaler technique checklists as these tools only measured the correct sequence of steps for the correct use of specific devices.

Table 2.1 Definitions	s and examples of health literacy (HL) domains
Domain	Definition/example
Access	Being able to navigate and find health information - it is more than the availability of information and services.
	It is mediated by education, culture and language, by the communication skills of professionals, by the nature
	of materials and messages, and by the settings in which health-related supports are provided – Canadian
	Expert Panel on Health Literacy (CEPHL) [29].
	o e.g., I have the skills to FIND the health information I want.
Understand	Knowledge about a subject or situation, and comprehension of the health condition and information –
	Cambridge Dictionaries [55].
	o e.g., How confident do you feel you are able to follow the instructions on the label of your inhaler?
Evaluate	To be able to determine whether information/service is applicable to self - to judge or calculate the quality,
	importance, truthfulness, or value of information – Cambridge Dictionaries [56].
	o e.g., I have the skills to JUDGE which health information can be trusted.
Communicate	To share information with others (doctor, caregiver, family members, etc.) by speaking, writing, and body
	language – Cambridge Dictionaries [57].
	o e.g., I have the skills to DESCRIBE my health concerns to others.
Use	Adapting and applying information to daily life for disease management - to take, hold, or deploy information
	as a means of accomplishing or achieving health outcome – Oxford Dictionaries [58].
	o e.g., I can use the information received from doctor/hospital to set my disease management goal.
Health numeracy	The degree to which individuals have the capacity to access, process, interpret, communicate, and act on
	numerical, quantitative, graphical, biostatistical, and probabilistic health information needed to make
	effective health decisions [30].

2.2.2 Search strategy

To better understand the concept of HL prior to this systematic review, I examined studies from five [39,49,51,59,60] systematic reviews focusing on general HL measurement. The five reviews identified and evaluated generic HL tools assessing various domains such as reading comprehension, word recognition, and numeracy. This pilot stage enabled me to identify MeSH headings which were used to develop a preliminary search strategy. The search strategy included the search concepts: health literacy domains

(access OR understand OR evaluate OR communicate OR use OR numeracy) AND measurement AND chronic diseases (asthma OR COPD) AND 1974-2016 AND English. The search strategy is presented in Figure 2.1.





2.2.3 Data sources and selection

The search was developed in MEDLINE (Ovid) by a librarian using the search strategy mentioned above. Embase (Ovid) was then searched using a refined search based on the included studies from MEDLINE. Details of the literature search are provided in Appendix A. The final search was performed in July 2016 and was limited to the years 1974 to 2016 and English language publications on HL tools. Reference lists of included studies for additional papers were handsearched as well as grey literature including unpublished reports and dissertations. The search was further supplemented with documents shared by the instrument development study advisory panel (AP) which consisted of national and international HL experts. Search results were imported into RefWorks and duplicates were removed before review. The study selection process for both the titles and abstracts and full-text articles stages were pilot tested with myself and another reviewer. Another reviewer and I independently assessed titles and abstracts identified from the MEDLINE and Embase searches by applying the eligibility criteria during study selection. Any disagreements were resolved by a third reviewer. Full studies of included titles and abstracts were retrieved for further review and were again assessed independently by myself and another reviewer. The third reviewer resolved all disagreements again from the full-text articles review stage. The Cohen's kappa for the full-text articles review stage was 0.83. Following, measurement tools of the included articles after full review were identified and sought for extraction. Tools that were not in the article or provided as supplements had to be handsearched through reference lists of papers. Authors of relevant studies were contacted to obtain missing data where appropriate.

2.2.4 Data extraction and synthesis

Another reviewer and I independently extracted content from the included measurement tools and corresponding studies using standardized data extraction forms (one for mapping tool items to HL domains and one for development, use, and/or validation studies). The data extraction forms can be found in Appendix B. Information on tools and studies including general information such as author(s), title, year published, and country of origin; study characteristics such as study design and population; instrument details including HL domains, underlying content, purpose, number and type of categories, scale design, and scoring; and utility characteristics, for example, level of reading ability, and strengths and weaknesses were extracted. Disagreements on mapping of tool items to appropriate HL domains were resolved by a third reviewer. Inter-rater agreement was assessed between myself and the other

reviewer with 81.96% agreement on the total tools. The first five studies of three tools were pilot tested to ensure agreement and clarification between the reviewers before continuation.

The identified tools were first organized according to assessment of HL domains, disease, and then validation following data extraction. Each tool was reviewed in-depth to identify the distribution of domains, its content, and important characteristics. Due to too much heterogeneity of tools, the data is presented in a descriptive form. Validated tools were assessed using a checklist that was developed exclusively in this study to rate key components available for each tool. Key components included: (1) a conceptual model or framework behind item development; (2) complete assessment of all five HL domains; and (3) detailed descriptions of scoring and validation processes such as psychometric properties. The checklist for reporting key components of validated tools is provided in Appendix C.

2.3 Results

A systematic review was undertaken, following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines for reporting systematic reviews [61]. The MEDLINE (Ovid) search produced 1326 publications and the Embase (Ovid) search produced 1846 publications. In addition, eight reviews and 50 papers regarding HL measurement were shared by the study AP and added to the review. In total, 2860 articles were screened after removal of duplicates, from which 1775 articles were excluded after title and abstract review. Another 984 articles were excluded upon full-text review. Reasons for exclusion included: no measurement tool (n= 425), not assessing any of the HL domains (n=403), unrelated target populations (n=149), and tool not in English (n=7). Tools were then sought from the 101 articles included in the review which resulted in an addition of 13 studies found through references. Ultimately, the search yielded 65 measurement tools of which 40 were asthma-specific, 22 were COPD-specific, and

3 were asthma/COPD-specific. Figure 2.2 contains the PRISMA flow diagram of selected studies for this review.



Figure 2.2 PRISMA flow diagram of selected studies

2.3.1 Characteristics of measurement tools

The content of identified tools was largely focused on disease physiology and etiology; identifying and controlling of triggers; recognition of symptoms and assessing symptom severity; and self-management

knowledge such as the use of medications, monitoring and recording of peak flow rate, and the ability to follow an action plan. Various measurement tools had been designed to collect data on the participation and perceptions of pulmonary rehabilitation programs among COPD patients as well as identifying and evaluating sources of education. The number of items ranged from 2 to 157 and types of response options and scaling varied between items in the identified tools including: true/false/not sure, yes/no, multiple choice, Likert-type scales, and open-ended responses. Readability was only reported in six [62-67] tools and varied from 5th -11th grade reading levels. In terms of administration, 30 [63,65,66,68-94] tools were self-administered; 14 [64,95-107] were interviewer-administered; and 21 [62,67,108-126] did not report on administration mode.

The following five [62,64,86,87,94] measurement tools are case examples of tools used to describe the spectrum of characteristics of included tools. These validated tools were selected for highlighting by reviewing the 65 tools for variation across different characteristics such as disease, underlying content, purpose, number of items, types of response options, scoring, and mode of administration. The Asthma General Knowledge Questionnaire for Adults with Asthma [62] is a 31 item tool developed for use in an RCT to assess the knowledge of asthma concepts (e.g., asthma attacks, medications, and triggers) in an education program. Questions are marked as either 'true', 'false', or 'not sure' with the total of correct answers indicating a knowledge score. Mode of administration for this tool was not reported. The Asthma Self-Management Questionnaire (ASMQ) [64] is another asthma-specific tool developed for the purpose of measuring patients' general knowledge of asthma. Knowledge on preventive strategies, proper use of inhalers, differences between maintenance and rescue medications, and use of peak flow meters are assessed through 16 multiple choice questions with one point assigned to each correct response and a total score equaling the sum of all points. The tool was developed using information received from

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patients participating in a trial on improving asthma-related quality of life. In the trial, patients were asked open-ended questions on how asthma affected their daily lives and what they did to manage their disease. Patients' comments were used to formulate the items and corresponding response options, and the developed questions and response options were then reviewed again with patients for their feedback and modifications. The ASMQ is interviewer-administered. For COPD-specific tools, the Bristol COPD Knowledge Questionnaire (BCKQ) [87] has 65 items and contains topics on epidemiology and physiology; aetiology; common symptoms: breathlessness, phlegm (sputum); chest infections/exacerbations; exercise; smoking; vaccinations; inhaled bronchodilators and corticosteroids; antibiotic treatment; and steroid tablets. Questions are marked as either 'true', 'false', or 'don't know' with a score being given for a correct answer and no scores for an incorrect answer or a 'don't know' response. The tool is selfadministered. The Lung Information Needs Questionnaire (LINQ) [86] is an alternative from COPD-specific knowledge questionnaires and was designed to measure 'information needs' from a patient's perspective in terms of what the patient wants to know. The final LINQ has 17 items in six topics: disease knowledge; medicines; self-management; smoking; exercise; and diet. This questionnaire has an easy-to-use format and was designed with patient-centered wording to improve patient comprehension of the meaning of the questions [127]. Questions were developed through patient focus groups to establish information needs as perceived by patients themselves with wording of items and response options further reviewed again in supplementary focus groups. Five of the domain scores are calculated by the sum of item scores in each domain where '0' indicates no information need and '1-3' indicating a level of need. In the case of the smoking domain, non-smokers were given a domain score of '0' and current smokers were given a domain score of the sum of the three smoking questions. The LINQ is self-administered. For asthma/COPD-specific tools, the European Health Literacy Survey Questionnaire (HLS-EU-Q) [94] has 88 items and was developed using a conceptual model of HL derived from a systematic literature review of

existing HL definitions and conceptualizations [60]. The core model consists of a 12 cell matrix with key processes of 'accessing', 'understanding', 'appraising', and 'applying' health-related information within three areas: healthcare; disease prevention; and health promotion. Item generation and face validity of the tool were tested in focus groups with the general population. Questions of the HLS-EU-Q are answered on a Likert-type scale ranging from 'very easy', 'easy', 'difficult' to 'very difficult'. The tool is self-administered.

The characteristics of asthma-specific tools are presented in Table 2.2, COPD-specific tools in Table 2.3, and asthma/COPD-specific tools in Table 2.4.

Table 2.2 Characteristics of asthma measurement tools									
Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)	
		items and							
		scales							
Asthma General Knowledge	Asthma physiology and	31;	SMOG	Not reported	The knowledge score	The study findings	Not reported	Understand	
Questionnaire for Adults with	aetiology; identification and	True/False/Not	formula		was the total of correct	suggest that the tool			
Asthma [62]	control of triggers; recognition	sure	estimated 5-6		answers	was a valid and reliable			
	of symptoms and assessment		years of			measure for assessing			
	of symptom severity;		schooling			the asthma general			
	medications; lifestyle factors;					knowledge of			
	psychosocial factors; inhaler					adults attending the			
	and peak flow meter skills; and					asthma education			
	monitoring and recording of					program			
	peak flow rate								
12-Item Consumer Asthma	Asthma medication and	12;	Flesch-Kincaid	Self-	One mark is allocated	Simple and reliable	Not reported	Understand	
Knowledge Questionnaire (Cq)	asthma management	True/False/Bla	Grade Level	administered	to each correct answer	instrument for			
with a True/False Response	knowledge; the tool was	nk	Score of 8.1,		and 0 for each	assessment of asthma			
[63]	developed from the current		indicating that		incorrect answer or	knowledge			
	National Asthma Council of		an eighth		each question that was				
	Australia guidelines		grader		left unanswered				
			(average age						
			13 years)						

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
Asthma Self-Management	Knowledge of preventive	16; multiple	Flesch-Kincaid	Interviewer-	One point is assigned	The tool was shown to	The tool was	Understand
Questionnaire (ASMQ) [64]	strategies, proper use of	choice	Grade Level	administered	to each correct	be valid, reliable, and	developed in an urban	
	inhalers, differences between		Score of 6.8		response, and the raw	responsive; also	primary care practice	
	maintenance and rescue				score equals the sum	patient-derived	and may not reflect	
	medications and use of peak				of all points; (raw		self-management	
	flow meters				score/16) x 100 and		issues of patients in	
					ranges from 0 to 100		other settings	
					with a higher score			
					indicating more			
					knowledge of self-			
					management			

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
Asthma Knowledge	Based on the five knowledge	11; True/False	Not reported	Self-	Scored as a percentage	Not reported	Not reported	Understand
Questionnaire [68]	areas recommended for			administered	of correct responses			
	patient education by the							
	National Asthma Education and							
	Prevention Program 1997							
	guidelines: basic facts about							
	asthma, the role of							
	medications, skills, e.g., inhaler							
	use, the role of environmental							
	triggers and trigger avoidance,							
	and when and how to take							
	rescue actions							
Check your asthma "IQ" [108]	Awareness of issues related to	12; True/False	Not reported	Not reported	One point is assigned	Not reported	Not reported	Understand
	asthma				to each correct			
					response with a higher			
					score indicating more			
					knowledge of asthma			

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
Asthma self-management	(1) Asthma pathophysiology:	24; True/False	Flesch-Kincaid	Self-	One point is assigned	Enhanced clinical utility	Factor analysis	Understand
knowledge questionnaire [65]	the contrast between normal		Grade Level	administered	to each correct		suggested that there	
	and asthmatic lungs; what		Score of 5.2		response with a higher		may be more than five	
	happens to the airways in an				score indicating more		content areas of	
	asthma attack; common				knowledge of asthma		knowledge needed for	
	symptoms of asthma (cough,						self-management	
	wheeze, chest tightness, and							
	shortness of breath); (2) roles							
	of medications: quick-relief							
	medicines (albuterol); long-							
	term control (preventive							
	medicines) such as inhaled							
	corticosteroids; (3) skills:							
	inhaler/spacer/holding							
	chamber/self-monitoring:							
	inhaler use; spacer/holding							
	chamber use; self-monitoring							
	with peak flow meter; cleaning							
	inhalers and knowing when							

they are en	npty; (4)							
environme	ntal control							
measures:	dust mites; tobacco							
smoke; anii	mal dander;							
cockroache	s; mold/pollens;							
vacuum cle	aning; (5) when and							
how to take	e rescue actions:							
how to kno	w asthma is getting							
worse; mar	naging an asthma							
attack; whe	n to obtain help for							
acute asthr	na							
Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
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		items and						
		scalos						
		scales						
The Knowledge, Attitude, and	(a) The patient's attitude	60: 20 items	Not reported	Not reported	A perfect score on the	The KASE-AQ allows	Not reported	Access,
Self-Efficacy Asthma	toward the illness, including his	related to			knowledge subscale of	physicians and		Understand,
Questionnaire (KASE-AQ) [109]	or her willingness to work with	asthma			the KASE-AQ is 20; the	behavioral scientists to		Evaluate, Use
	the physician to manage the	knowledge,			maximum score a	determine to what		
	disorder; (b) the patient's	20 items			subject can attain on	extent a patient's lack		
	confidence in his or her ability	related to			the attitude subscale is	of knowledge,		
	to contribute to the	patient			100: the higher an	uncooperative		
	management of the illness; and	attitude, and			individual's	attitude, or low self-		
	(c) the patients knowledge	20 items			score, the more	efficacy may be		
	regarding the illness, which	related to			positive the individual's	contributing to		
	enables the patient to perform	patient self-			attitude	difficulties the patient		
	appropriate procedures to	efficacy;			regarding his or her	is experiencing		
	control particular	multiple choice			asthma and the more	in managing the		
	symptoms				the person	asthma-difficulties that		
					is willing to work in	cannot be explained by		
					cooperation with a	other factors such as a		
					physician to	respiratory infection,		
					manage the illness; the	seasonal allergies, or a		
					maximum score a			

		subject can attain on	need for different or	
		the self efficacy	increased medication	
		subscale is 100: the		
		higher an individual's		
		score, the more		
		confident the		
		individual is about		
		managing his or her		
		asthma, avoiding		
		asthma triggers, and		
		controlling the disorder		

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		items and						
		scales						
Asthma Numeracy	Developed from a series of	4; Free text,	Not reported	Interviewer-	1 if correct and 0 if	It assess some of the	The questionnaire is	Numeracy
Questionnaire (ANQ) [95]	potential survey items from	multiple choice		administered	incorrect	most commonly used	brief and is not a	
	common recommendations					numerical concepts in	comprehensive	
	made to patients with					asthma education and	assessment of asthma	
	moderate or severe asthma					it can easily be used in	numeracy	
	adapted from current national					clinical care or added		
	guidelines					to a clinical research		
						protocol		

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		items and						
		scales						
Asthma Knowledge in Tertiary	Basic facts of asthma, role of	9; Yes/No/	Not reported	Interviewer-	One point is assigned	Not reported	Not reported	Access,
Care Asthmatics [96]	medications, a track	Don't know,		administered	to each correct answer,			Understand,
	management skills through use	Check (all) that			while incorrect or			Use
	of a written action plan	apply			unsure responses were			
					accorded a zero score.			
					Knowledge statements			
					were analyzed			
					individually and as a			
					summed score. The			
					lowest and highest			
					total scores possible			
					were 0 and 6,			
					respectively.			

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
Patient-Clinician	Patient knowledge of the	6; Definitely	Not reported	Interviewer-	Questions were	It was the first	Not reported	Access,
Communication [97]	function of inhaled steroids	true/ mostly		administered	converted to a	validated instrument		Communicate,
	and patient-clinician	true/ don't			numerical metric with	for assessing patient		Use
	communication	know/ most			higher scores	knowledge of the		
		likely false/			representing better	function of inhaled		
		and definitely			communication for the	steroids and patient-		
		false			patient-clinician	clinician		
					communication	communication		
					questionnaire/ more			
					knowledge for the			
					function of inhaled			
					steroids. The total			
					score could range from			
					6 to 30.			

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
Hypothetical Asthma Attacks	Two scenarios: the first was an	16; open-	Not reported	Interviewer-	There was a 25-point	Scenarios may be a	Not reported	Use
[98]	attack of increasing severity	ended		administered	scale on which 0	tool that can be used		
	over 7 days (slow onset) while				represented a total	to assess the true		
	the second described an attack				lack of appropriate	efficacy of teaching,		
	that developed over 1 h (rapid				responses and a score	particularly in high-risk		
	onset). Both scenarios ended				of 25 was an optimal	patients who are		
	with the subject "experiencing"				response. Respiratory	justifiably targeted in		
	a severe attack such that				physicians associated	asthma education		
	he/she was so wheezy and				with the study	programs. There was		
	short of breath as to be unable				considered a score of	excellent interrater		
	to speak or rise from a chair. At				15 or greater would	and intrarater		
	three stages during each of the				indicate a satisfactory	consistency in scenario		
	scenarios, subjects were asked				level of asthma self-	response scores.		
	to describe what action they				management			
	would normally undertake if				knowledge. Subject			
	they were actually				responses were scored			
	experiencing such symptoms.				according to the			
					appropriateness of			
					actions taken relevant			
	1	1		1	1	1		

		to the stage of the		
		attack, e.g., seeking		
		medical advice was		
		considered		
		inappropriate in the		
		initial stage of the		
		attack and therefore		
		did not score points,		
		whereas at a later		
		stage, when		
		appropriate, it did.		
		Scores were weighted		
		for strategies		
		considered most		
		important in aborting		
		an attack or to be		
		potentially lifesaving.		
		Negative scoring was		
		not used.		

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
Asthma Knowledge and Self	Asthma physiology and	11; 5-point	Not reported	Not reported	Knowledge: scored as 0	Not reported	Not reported	Understand,
Management Behaviour [110]	severity, medications, and the	Likert-type			for the three			Use
	use of a crisis management	scale			statements at the			
	plan				incorrect end of the			
					scale to 2 and 4 for the			
					options at the correct			
					end; Self management			
					behaviour: scored with			
					a 5 point Likert-type			
					scale. A high score			
					indicated desired or			
					appropriate behaviour.			
Use of MDIs in Hospital	Degree of knowledge of MDIs	34; Yes/No,	Not reported	Interviewer-	Not reported	Not reported	Not reported	Access,
Environments [99]	(duration, the type and dosage	open-ended,		administered				Understand,
	and schedule of the MDIs and	Check (all) that						Evaluate
	whether or not the instruction	apply						
	was provided)							

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
Asthma Behaviour Change	The questionnaire covered two	45; Yes/No	Not reported	Self-	One point for a right	It is a valid tool	Not reported	Understand,
(ABC) [69]	concepts: behaviour and			administered	response, two for 'does			Evaluate, Use
	knowledge. The behaviour				not know', three for a			
	component was constituted of				wrong response and			
	seven different clinical				four for missing data.			
	situations in term of severity of				The right/wrong			
	asthma and the knowledge				response could be 'yes'			
	component was composed of				or 'no' depending on			
	two dimensions measuring				the item. Each			
	knowledge of pathophysiology				dimension score was			
	and of therapeutic areas.				calculated by the sum			
					of score item			
					responses, then, the			
					result was transformed			
					to range from 1 to 100,			
					with 0 being the best			
					score and 100 the			
					worst score.			

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
Allergy/Asthma Knowledge	Two methods were used to	11; True/False,	Not reported	Self-	First questionnaire for	Not reported	Not reported	Understand
Assessment [70]	assess the participants'	open-ended		administered	asthma knowledge was			
	knowledge: the first was a 10-				10 items questionnaire			
	item true/false allergy/asthma				with one point is			
	quiz; the second was an				assigned to each			
	allergy/asthma schema based				correct answer. Second			
	evaluation in which				one which was			
	participants were asked to				allergy/asthma			
	write the name and the				schema: one point was			
	mechanism of action for each				given for all correct			
	allergy/asthma medication				information (albuterol:			
	they were taking				reliever inhaler) and			
					half a point was given			
					for partially correct			
					information (albuterol:			
					controller inhaler).			

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
Are You an Asthma ACE? [71]	Asthma knowledge (general	16; True/False	Not reported	Self-	One point is assigned	The survey instrument	Some questions were	Understand
	knowledge, knowledge of			administered	to each correct	was a powerful	too basic (i.e., those in	
	pathophysiology, disease				response	educational tool,	the general knowledge	
	management)					capable of sensitizing	subgroup), those that	
						event participants to	were poorly covered or	
						the issues that would	not covered during the	
						be addressed in the	one-night educational	
						lecture series	intervention, and those	
							that appeared to have	
							value in measuring the	
							impact of the	
							intervention	
Clinician's Communication	Examining what adult patients	8; Likert-type	Not reported	Self-	Not reported	Not reported	Not reported	Understand,
Behaviour [72]	with asthma report about their	scale		administered				Communicate
	experiences with their own							
	self-management behavior and							
	their experiences working with							
	their clinicians to control							
	asthma							

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		items and						
		scales						
Patient's Knowledge about	Demographics, asthma	22; multiple	Not reported	Self-	The question	Not reported	Not reported	Access,
Asthma Treatment [73]	medication, symptoms, allergy,	choice, open-		administered	about sufficient			Understand,
	emergency consultations,	ended			knowledge was scored:			Evaluate, Use
	smoking habits, occupation,				"yes, absolutely",			
	sick				"yes, partially" and			
	leave, and the patient's				"no"			
	knowledge about asthma							
	treatment							
Patient Knowledge of Asthma	Pulmonary function and	11; Yes/No	Not reported	Not reported	Not reported	Not reported	Not reported	Access,
and its Treatment [111]	symptoms; eosinophil cationic							Understand
	protein as a marker of							
	inflammatory activity in the							
	airways; emergency visits; and							
	patient knowledge of asthma							
	and its treatment.							

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
Questionnaire for the	Pathophysiology of asthma;	22; Yes/No,	Not reported	Self-	Not reported	Not reported	Instrument does not	Understand,
Evaluation of Clinical	environmental control;	multiple		administered			evaluate psychological	Use
Improvement and of the	triggering/irritating factors;	choice, Check					aspects, health-related	
Degree of Knowledge [74]	treatment of asthma;	(all) that apply,					quality of life, cognitive	
	inhalation technique with and	analogue scale					aspects, or	
	without a spacer	from 0 to 10					psychosocial behaviour	
Career Choice in Young Adults	Areas assessed included	30; Yes/No,	Not reported	Self-	The occupation score	Assessment of asthma	Not reported	Access,
with Asthma [75]	asthma management,	open-ended,		administered	was coded from 1 to 8,	knowledge can be		Understand
	symptom experience, career	Check (all) that			with a score of 1	regarded as a best-case		
	choices, and demographic and	apply, Likert-			corresponding to a	scenario for awareness		
	socioeconomic information	type scale			highranked	of asthma as a factor in		
					occupation (i.e., high	career choice. It is		
					executive or	possible that		
					professional) and a	awareness may be		
					score of 8	lower for less		
					corresponding to a	advantaged		
					low-ranked occupation	adolescents.		
					(i.e., unemployed			
					or homemaker)			

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		items und						
		scales						
Knowledge and Attitudes of	Knowledge and attitudes	15; Yes/No	Not reported	Self-	"Do not know"	Practical oriented-	Not reported	Understand,
Asthma [76]	towards asthma as a disease			administered	answers were recorded	short scale is easy to		Use
	and its medications				as wrong answers	use in community		
					yielding 0 points. Each	pharmacy and it gives a		
					correct answer yielded	rough information		
					1 point. The knowledge	about patients'		
					scores were calculated	attitudes towards the		
					by summing up correct	disease and the		
					answers for disease-	treatment to a		
					related statements	pharmacist for		
					(score range 0-7) and	monitoring the		
					for medication-related	outcomes		
					statements (score			
					range 0-8)			

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
Patient Asthma Concerns Tool	Items were grouped under the	14: Check (all)	Not reported	Interviewer-	Not reported	The PACT	Not reported	Access, Use
(PACT) [100]	domains of: diagnosis,	that apply, 5-		administered		questionnaire provides		
	symptoms, management	point Likert-				a robust validated		
	behaviour, medication	type scale, 4-				instrument, applicable		
	adherence and barriers,	point Likert-				and acceptable to		
	practitioner care, patient	type scale,				general practitioners,		
	knowledge, beliefs,	Yes/No, open-				with which to explore		
	and exacerbation concerns	ended				and define the unmet		
						needs of older people		
						with asthma. It is		
						believed the use of the		
						PACT in clinical care		
						will facilitate tailored		
						asthma management		
						and education to		
						improve current		
						asthma management		
						behaviours and		
						outcomes in older		

			people. Careful	
			construction and	
			testing of the	
			instrument means that	
			PACT is well validated	
			in a group of older	
			people with asthma	
			drawn from	
			community settings	
			and is likely to be	
			applicable to them.	
1				

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
Knowledge about Asthma,	Sources of knowledge about	7; multiple	Not reported	Not reported	Not reported	Not reported	Not reported	Access,
Fasting, and Medication Use	asthma, fasting, and	choice, Check						Evaluate, Use
[112]	medication use	(all) that apply						
Asthma Questionnaire [113]	Designed to test how well the	15; open-	Not reported	Not reported	If a patient answered	Not reported	Not reported	Access,
	primary health care team had	ended, Yes/No			no to all questions they			Understand,
	educated registered asthma				were given a LOW			Use
	patients or their guardians				morbidity, yes to one			
	about all aspects of their				question they were			
	condition				classed as MEDIUM			
Medical Interview Satisfaction	Four subscales (communication	21; 7-point	Not reported	Self-	Not reported	It is a valid and reliable	Not reported	Access,
Scale (MISS-21) [77]	comfort, distress relief,	Likert-type		administered		instrument for the		Understand,
	compliance intent, and	scale				assessment of patient		Evaluate,
	rapport)					satisfaction with		Communicate,
						individual		Use
						consultations in British		
						general practice		

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
Asthma Opinion Survey [114]	Vulnerability, perceived quality	18; 5-point	Not reported	Not reported	Scores are computed	Item content is	Not reported	Access,
	of care, recognition and control	Likert-type			for three factors by	appropriate for the		Understand,
		scale			summing the items	general population of		Evaluate
					that loaded on that	asthma patients and		
					factor. The scoring for	only takes a few		
					some items is reversed	minutes to respond to.		
					in computing the total			
					score on the factor:			
					items 5, 8, 11, and 17.			
Physician's Participatory	Patients' rating of physicians'	3; 6-point	Not reported	Self-	Not reported	Not reported	Relies on patients'	Access
Decision-Making Style [78]	propensity to: 1) involve them	Likert-type		administered			reports	
	in treatment decisions; 2) give	scale						
	them a sense of control over							
	medical care; and 3) ask them							
	to take some responsibility							

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
Survey of Medicaid Recipients	Key components of asthma	41; Yes/No,	Not reported	Self-	Not reported	Not reported	Recall bias and	Access,
with Asthma [79]	care including health	Likert-type		administered			respondents reporting	Understand,
	assessments, medication use,	scale					what they believe is	Communicate,
	exposure to tobacco smoke,						the "right" answer	Use
	patient education and							
	comprehension, ability to self-							
	manage based on changes in							
	symptoms or peak flow							
	readings, access to providers,							
	availability of asthma-related							
	equipment, and overall							
	satisfaction with asthma care							

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		Stanna and						
		items and						
		scales						
A (A.1) [445]	6	a. x. /b.					N	
Awareness of Asthma [115]	Awareness of asthma	2; Yes/No	Not reported	Not reported	If the answer was "yes"	Not reported	Not reported	Access
					to one of the			
					questions, the subjects			
					were classified as being			
					aware of asthma.			
					Subjects who were not			
					aware of having			
					asthma, but who were			
					diagnosed with asthma			
					in this survey were			
					classified as unaware			
					asthmatics.			

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
Perceived Access to Care [80]	Patients' experience re	3; Yes/No	Not reported	Self-	Not reported	Not reported	Not reported	Access
	reaching a practitioner by			administered				
	phone, accessing a clinic							
	appointment or obtaining							
	asthma medication							
Medication and Inhaler	Adherence to medication use	12; Yes/No	Not reported	Self-	On each item the "no"	Scales detect impact of	Not reported	Use
Adherence Scale [81]	and inhaler use			administered	response indicated	intervention designed		
					better adherence	to improve adherence;		
						easy to use and can be		
						completed in less than		
						5 minutes; no risk and		
						little psychological		
						discomfort involved		

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
Asthma Therapy Assessment	Individual's self-reported	24;	Not reported	Self-	Responses were	Not reported	Not reported	Access,
Questionnaire (ATAQ) [82]	severity of asthma symptoms,	Yes/No/Unsure		administered	summed to produce			Evaluate,
	medication compliance				scores			Communicate,
	barriers, deficiency in							Use
	knowledge of							
	asthma, and barriers to							
	effective communication with							
	his or her healthcare provider							
Knowledge of the Asthma	Asthma knowledge	5; I agree/I	Not reported	Not reported	Not reported	Not reported	Not reported	Understand
Disease [116]		disagree/I						
		don't know						

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
Asthma Knowledge	Etiology of asthma,	28;	Not reported	Interviewer-	All responses marked	Not reported	Not reported	Understand,
Questionnaire [101]	pathophysiology, symptoms	Yes/No/Can't		administered	as "yes" get 1 point			Evaluate
	and assessment of severity,	say			except where "no" is			
	medication, prevention,				the correct answer. All			
	natural history				responses marked "no"			
					or "can't say" get 0			
					point. A final score was			
					obtained by summing			
					these scores. The			
					maximum possible			
					score was 28. The			
					scores were expressed			
					as percentage of the			
					maximum possible			
					score.			

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
Judgement Skills Scale [83]	Developed based on the	18;	Not reported	Self-	Each response option	Tool assesses patient	Not reported	Understand,
	Situational Judgment Test	hypothetical		administered	has a score from 1	ability to use health		Evaluate,
	format; typical asthma self-	scenario			(most inadequate) to 4	knowledge according		Communicate,
	management situations	situations and			(most adequate). The	to the situation;		Use
	where the patient faces a	plausible			scores for the 19	assessing these skills,		
	problem, and a list of possible	courses of			scenarios should be	particularly in the		
	response actions by the patient	actions			summed up resulting in	context of chronic		
	is provided: (a) doctor-patient				a minimum score of 19	diseases, is important		
	communication, (b) medicine				and a maximum of 76.	since self-management		
	usage, (c) information seeking,					plays a key role in the		
	(d) trigger avoidance, (e)					daily care of a health		
	symptom recognition, and (f)					condition. The use of		
	exercise					the situational		
						judgment test for the		
						questionnaire has been		
						recognized for		
						successfully predicting		
						individuals'		
						performance, and		

			appropriate use of	
			knowledge according	
			to the situation. The	
			use of a Delphi	
			procedure to validate	
			the adequacy of the	
			response options from	
			a medical point of view	
			also reinforces the	
			validity of the tool.	

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
Knowledge and Attitude	Questionnaire contains	14; Yes/No, 4-	Not reported	Not reported	Not reported	The opportunity	Not reported	Understand,
Assessment [117]	components to assess the	point Likert-				to identify reasons for		Evaluate
	knowledge and attitude of	type scale				non adherence		
	asthma patients towards their					through a simple		
	disease and treatment					assessment will allow a		
						tailored intervention to		
						be planned for each		
						patient		
Patient-Physician	Patient-physician	2; Yes/No	Not reported	Interviewer-	Not reported	Not reported	Not reported	Access,
Communication about Work-	communication about asthma			administered				Communicate
related Asthma [102]	associated with work							
						1	1	

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
1600 REALISE ASIA Asthma	Comparing asthma symptoms	157; Check (all)	Not reported	Self-	Not reported	Not reported	Survey relied on	Access,
Patient Survey Questionnaire	and indicators of acute	that apply,		administered			patients' responses to	Understand,
[84]	exacerbations across guideline-	open-ended,					the online	Evaluate,
	defined control levels and	Yes/No, Likert-					questionnaire. These	Communicate,
	treatment types, patients'	type scale					responses could not be	Use
	perceptions of asthma and						clinically verified, and	
	attitudes toward asthma						some patients might	
	management, sources of						have inaccurately	
	information and asking what						recalled certain events.	
	the term "well-controlled						Respondents were	
	asthma" meant						patients who used	
							social media and may	
							not represent the	
							cross-section of the	
							asthmatic population.	

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
Knowledge, Attitude, and	Patient's perceptions about the	16; multiple	Not reported	Not reported	Not reported	Not reported	Not reported	Understand,
Practice (KAP) [118]	disease, their attitude towards	choice, Check						Evaluate, Use
	it (its symptoms, causes and	(all) that apply,						
	risk factors) and their practice	Yes/No/Don't						
	of living with the disease	know						

Table 2.3 Characteristics of COPD me	easurement tools							
Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
Practice assessment in COPD [85]	COPD management e.g.,	18; The	Not reported	Self-	Not reported	Not reported	Not reported	Access,
	participation in pulmonary	number and		administered				Understand,
	rehabilitation programs and	type of						Use
	current medication; and	response						
	patient perceptions of	options vary						
	symptoms, knowledge of	between items,						
	disease and sources of	e.g., frequency,						
	education	Likert-type						
		scale, select all						
		that apply						

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
The Lung Information Needs	Domains: disease	17; The	Not reported	Self-	Five of the domain	The LINQ assesses	The LINQ does not	Access,
Questionnaire (LINQ) [86]	knowledge; medicines; self-	number and		administered	scores: sum of scores	areas that may be of	cover all areas that	Understand,
	management; smoking;	type of			in each domain where	concern to patients; it	may require	Use
	exercise; diet	response			0 = no information	is a short	educational focus for a	
		options vary			need and 1–3 indicates	questionnaire which is	particular patient, e.g.,	
		between items,			a level of need;	easy to use in a clinical	information need	
		e.g., 0,1,2,3,			Smoking domain: all	context	about sexuality is not	
		missing			patients who were		covered	
					nonsmokers were			
					given a domain score			
					of 0 irrespective of			
					their response to the			
					remaining two smoking			
					questions; Current			
					smokers were given a			
					domain score that was			
					the sum of the three			
					smoking questions			

Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
items and						
scales						
d 65;	Not reported	Self-	Positive scoring	Easy to score, and	Not reported	Understand
ology, True/False/Do		administered	was used with a mark	therefore would		
oms, n't know			being given for a	be suitable for routine		
bhlegm,			correct answer, but no	use in both clinical, and		
exercise,			mark awarded for an	research situations;		
ization,			incorrect answer or for	the topics chosen for		
dilators,			a 'don't know'	testing were those that		
steroids and			response	a patient with COPD		
				might reasonably be		
				expected to have		
				appropriate		
				knowledge; 'don't		
				know' option identifies		
				areas of lack of		
				knowledge		
	Number of items and scales d 65; ohogy, 7rue/False/Do oms, n't know ohlegm, 6 exercise, 7 ization, 6 dilators, 7 steroids and 7	Number of items and scalesReadabilityd65;Not reportedology,True/False/DoInterformationohlegm,n't knowInterformationexercise,InterformationInterformationdilators,InterformationInterformationsteroids andInterformationInterformation	Number of items and scales Readability Administration d scales items and items and d 65; Not reported Self- plogy, True/False/Do administered pms, n't know Intersection Intersection exercise, Intersection Intersection Intersection dilators, Intersection Intersection Intersection steroids and Intersection Intersection Intersection	Number of items and scalesReadability items and scalesAdministration of scalesScoringd65;Not reportedSelf- administeredPositive scoring was used with a mark being given for a correct answer, but no mark awarded for an incorrect answer or for a 'don't know'Self- administeredPositive scoring was used with a mark being given for a correct answer, but no incorrect answer or for a 'don't know'dilators, steroids andImage: Note of the state of the s	Number of tems and Readability Administration Scring Strengths items and scales -	Number of items and Readability (items and scles) Readability (items and scles) Administration Storing Strengths Weaknesses d scles soles soles

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
		Seales						
Understanding COPD	"About COPD": disease	24; Likert-type	SMOG grade	Self-	The scores of the	The tool is valid and	The readability of the	Access,
Questionnaire (UCOPD) [66]	education, recognizing and	scale	was 11.49,	administered	domains and sections	reliable. It has good	UCOPD questionnaire	Understand
	managing exacerbations,		reading age:		are calculated by	feasibility as it is self-	as assessed by the	
	medications; "managing		16/17 years		summing the scores of	administered, requires	SMOG formula was	
	symptoms of COPD":				the individual	no training and can be	higher than	
	managing dyspnea,				questions of that	completed and scored	recommended	
	conserving energy, benefit of				domain/section	in less than 10		
	exercise, managing low				(minimum score of all	minutes.		
	mood and depression,				domains/sections = 0;			
	managing anxiety and panic;				maximum scores:			
	"Accessing help and				About COPD domain			
	support": information on				=70, managing			
	welfare and benefits,				symptom of COPD			
	facilitates for ongoing				domain=70, accessing			
	exercise, information about				help and support			
	support groups, aids and				domain =40, Section			
	appliances; "satisfaction with				A=180 and section B			
	the education component of				which was satisfaction			
	pulmonary rehabilitation":				=50). The scores are			

amount of practical		then converted to		
amount of practical				
information contant of		norcontagos		
information, content of		percentages.		
education sessions, content				
of written materials,				
approachability of health				
professionals and				
accessibility of location				

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
Batalla Test (BT) [88]	It assesses patient's	3; Yes/No,	Not reported	Self-	Not reported	Not reported	Not reported	Understand
	understanding of their illness	open-ended		administered				
COPD Knowledge Questionnaire	medication use,	15; multiple	Not reported	Not reported	Not reported	Not reported	Not reported	Understand
[119]	management of dyspnea and	choice						
	exacerbations in COPD							
COPD Knowledge Quiz [120]	COPD knowledge	16; True/False	Not reported	Not reported	Not reported	Not reported	Not reported	Understand
COPD Learning Questionnaire	COPD pathophysiology and	20; multiple	Not reported	Not reported	Scoring system (range	Not reported	Not reported	Understand
[121]	lifestyles, medications and	choice			0 –20, higher score			
	rehabilitation, and oxygen				reflects greater			
	therapy				knowledge)			

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
COPD Patients' Knowledge	Patients' estimates of the	11; multiple	Not reported	Not reported	Not reported	Not reported	Not reported	Access,
regarding Cardiopulmonary	probability of survival after	choice,						Understand,
Resuscitation (CPR) [122]	CPR, the maximal length of	Yes/No/Someh						Evaluate
	time from collapse to CPR	ow, Check (all)						
	that allows a reasonable	that apply,						
	chance of survival and the	Likert-type						
	potential for "normalization"	scale						
	of quality of life 12 months							
	after CPR, understanding of							
	CPR, type and							
	frequency/month of							
	exposure to media dealing							
	with health-care, role of							
	fictional TV shows, TV							
	educational programs,							
	specialized publications and							
	websites, patients'							
	education, feelings about the							
	reliability of fictional medical							

shows and how they learned								
about the practice of CPR via								
the media								
	1	1		1				
Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
------------------------------	------------------------------	----------------	--------------	----------------	--------------	--------------	--------------	--------------
		itoms and						
		items and						
		scales						
Pulmonary Disease Knowledge	Kknowledge of chronic	20; True/False	Not reported	Not reported	Not reported	Not reported	Not reported	Understand
Test [123]	respiratory illness,							
	treatments, and self-							
	management							
COPD Awareness Questionnaire	Level of awareness of COPD	9; True/False,	Not reported	Self-	Not reported	Not reported	Not reported	Understand
[89]		Yes/No, open-		administered				
		ended						
COPD Patient Knowledge [124]	Disease process, symptom	14; True/False	Not reported	Not reported	Not reported	Not reported	Not reported	Understand
	recognition, treatment,							
	prevention, medications, and							
	good health practices							

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
Quality of Communication	General communication skills	19; 10-point	Not reported	Self-	A summary score was	The tool is a promising	Not reported	Access,
Questionnaire (QoC) [90]	and communication about	Likert		administered	created by adding the	questionnaire on the		Understand,
	end-of-life care	scale/Don't			scores for the	QOC to evaluate		Communicate
		know			individual items,	patient's perceptions		
					dividing by the number	of the quality of end-		
					of items answered by	of-life care		
					the patient and	communication		
					multiplying by 10 to			
					provide a score ranging			
					0–100			
Assessment of Care for Chronic	Patient	20; 5-point	Not reported	Self-	Each item was scored	It is a valid tool	Not reported	Access,
Conditions [91]	activation/involvement,	Likert-type		administered	on a 5-point scale	providing a brief,		Evaluate
	delivery system	scale			ranging from 1 (no or	patient-reported		
	design/decision support,				never) to 5 (yes or	assessment of the		
	goal setting/tailoring,				always)	extent to which		
	problem solving/contextual,					chronically ill patients		
	and follow up/coordination					report receiving care		
						that is congruent with		
						the chronic care model		

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
CONOCEPOC Study	Respiratory symptoms and	34;	Not reported	Interviewer-	Not reported	Not reported	Self-reported	Access,
Questionnaire [103]	diagnosis, knowledge of	Yes/No/Don't		administered			responses	Understand,
	COPD, spirometry use and	know, Check						Evaluate
	the perception of the	(all) that apply,						
	severity of other chronic	Likert-type						
	diseases, knowledge of the	scale						
	National COPD Strategy and							
	the new Anti-Tobacco Law							
Inhaled steroids in COPD	COPD and inhaled steroids	10;	Not reported	Not reported	Not reported	Not reported	Not reported	Understand
patients' specific Knowledge		True/False/Uns						
scale [125]		ure						
Barriers and Facilitators to End-	Barriers and facilitators	18;	Not reported	Interviewer-	Summary scores for	Not reported	Not reported	Access,
of-Life Care Communication	for patient-physician	Applies/Does		administered	barriers or facilitators,			Understand,
[104]	communication about end-	not apply/Do			comprised of the total			Evaluate,
	of-life care	not know			number of items			Communicate
					endorsed			

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
Seattle Obstructive Lung Disease	3 dimensions of life quality:	29; Likert-type	Not reported	Self-	Not reported	Internal consistency	Not reported	Evaluate
Questionnaire (SOLDQ) [92]	physical functioning,	scale		administered		and test-retest		
	emotional functioning, and					reliability, validity, and		
	coping skills					responsiveness to		
						change during and		
						after COPD		
						exacerbation were		
						found to be excellent.		
						Others have found the		
						SOLDQ to be a		
						powerful predictor of		
						both hospitalization		
						and all-cause mortality		
						in patients with		
						obstructive lung		
						disease.		

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
Quality of Communication	Physician-patient	5; Likert-type	Not reported	Interviewer-	Not reported	The quality of	Assesses only patients'	Evaluate
Questionnaire (QoC) 2 [105]	communication in general;	scale		administered		communication	perspective on patient-	
	overall satisfaction with					questionnaire may be a	physician	
	healthcare; and physician					useful tool for	communication	
	comfort talking about dying					evaluating		
						interventions		
						to improve		
						communication about		
						end-of-life care and		
						also has the advantage		
						of being less resource		
						intensive than expert		
						evaluation of		
						videotapes		
	healthcare; and physician comfort talking about dying					useful tool for evaluating interventions to improve communication about end-of-life care and also has the advantage of being less resource intensive than expert evaluation of videotapes	communication	

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
COPD Self-Management	Hypothetical scenarios based	39; Yes/No	Not reported	Interviewer-	Responses were scored	Not reported	Not reported	Use
Interview (COPD-SMI) [106]	on stages of an evolving			administered	separately for			
	exacerbation, i.e.,				knowledge and actions			
	maintenance when well,				(adherence) on a			
	early exacerbation and				three-point scale			
	severe exacerbation				(0–2) yielding a			
					maximum possible			
					score of 26 for both			
					the Knowledge Score			
					and the Action Score in			
					each scenario.			
					Higher scores implied			
					better self-			
					management for the			
					13 behaviours			
					assessed.			

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		items and						
		scales						
Evaluation of Pictorial COPD	Usual daily medication; what	31; open-	Not reported	Not reported	Not reported	The tool explores	Not reported	Understand
Action Plan [126]	to do when the patient	ended				patients' perceptions		
	experiences symptoms of an					about our images and		
	exacerbation, and finally,					whether they portray		
	what to do if it does not					what we want them to		
	improve					portray		
								1

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
Chronic Obstructive Pulmonary	COPD knowledge	21;	5th grade	Not reported	COPD-Q total score	The COPD-Q	The qualitative content	Understand
Disease Knowledge		True/False/Not	reading level		was calculated by	underwent a field test	validation process of	
Questionnaire (COPD-Q) [67]		sure	with an Flesch		assigning a score of 1	where 10 volunteers	the COPD-Q was	
			Reading Ease		for a correct response	confirmed the	subjective, leaving the	
			score of 74.7		and 0 for either an	understanding and	classification of item	
					incorrect or "not sure"	interpretation of each	importance to expert	
					response	COPD-Q item. The	reviewers' thoughts,	
						COPD-Q is written at a	opinions, and biases.	
						fifth grade reading		
						level which is		
						consistent with		
						recommended		
						guidelines. The COPD-		
						Q was found to have		
						acceptable internal		
						consistency and		
						significantly high test-		
						retest reliability.		

Table 2.4 Characteristics of asthm	a/COPD measurement tools							
Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
Health Literacy Screening	Access, understanding, and	3; 5-point	Not reported	Interviewer-	Scores were summed	It was validated	Not reported	Access,
Questions Assessment [107]	self efficacy	Likert-type		administered	to yield a total score of			Understand
		scale			3-15; higher scores			
					indicate better health			
					literacy			
Medication Adherence Report	Unintentional and	5; 5-point	Not reported	Self-	Scores are summed,	Not reported	Tool is inaccurate in	Use
Scale (MARS-5) [93]	intentional nonadherence	Likert-type		administered	and totals range from 5		identifying	
		scale			to 25, with higher		nonadherent users of	
					scores indicating		inhalation medication	
					higher self-reported		in patients with COPD	
					adherence.			

Title and reference	Topics covered	Number of	Readability	Administration	Scoring	Strengths	Weaknesses	HL domain(s)
		items and						
		scales						
		Scales						
European Health Literacy Survey	Access/obtain information	88; Likert-type	Not reported	Self-	Not reported	It is explicit build on a	The Delphi generated	Access,
Questionnaire (HLS-EU-Q) [94]	relevant to health;	scale/Don't		administered		definition and a	items mainly in the	Understand,
	understand information	know,				conceptual framework	domains of healthcare	Evaluate, Use
	relevant to health;	Yes/No/Don't				of health literacy. The	and disease prevention	
	process/appraise	know				tool is	and less in the domain	
	information relevant to					multi-dimensional in	of health promotion	
	health; apply/use					content and		
	information relevant to					distinguishes health		
	health on the domains of					literacy from		
	healthcare, disease					communication. It		
	prevention, and health					treats health literacy as		
	promotion					a 'latent construct' and		
						follows a principle of		
						compatibility.		
						It permits comparison		
						in different		
						populations and makes		
						reference to public		
						health rather than just		

			clinical use.	
			Participants and	
			external stakeholders	
			crucial decisions were	
			taken during the	
			development process.	
			· · · · · · · · · · · · · · · · · · ·	

2.3.2 Mapping of tool items to HL domains

Only two [77,84] out of the 65 measurement tools identified in this review assessed all five HL domains. The Medical Interview Satisfaction Scale (MISS-21) [77] is a modified and validated version of the MISS-29, a scale that was developed in the United States to assess patient satisfaction with individual doctor-patient consultations. The MISS-21 includes four subscales: 'Distress Relief', 'Communication Comfort', 'Rapport', and 'Compliance Intent' and asks the patient to indicate their level of agreement on a 7-point Likert-type scale. The tool has a total of 21 items of which 10 were found to be related to HL. Distribution of domains were fairly equal among the 10 items with two items for 'access', three for 'understand', two for 'evaluate', two for 'communicate', and one for 'use'. The 2012 REcognise Asthma and Llnk to Symptoms and Experience (REALISE) survey was revised to develop the 1600 REALISE ASIA Asthma Patient Survey Questionnaire [84], a non-validated online questionnaire-based survey assessing adult Asian subjects' asthma symptoms, exacerbations and treatment types, their perceptions and attitudes toward asthma and asthma management, and access to and evaluation of sources of asthma information. Types of response options include yes/no, multiple choice, Likert-type scales, and open-ended responses. The tool is comprised of 157 items of which 58 items assessed HL domains. Thirty-two items assessed 'use'.

Overall, the 'understand' domain was found to be the most frequently assessed domain among the 65 tools, being captured in 49 [62-77,79,83,84-90,94,96,99,101,103,104,106-126] of them with 20 (9 asthma [62-65,68,70,71,108,116] and 11 COPD [67,87-89,119-121,123-126]) tools assessing only that domain. Eight [62-65,67,68,87,126] out of the 20 tools had been validated. Tools that only assessed the 'understand' domain were largely 'knowledge' questionnaires such as the Chronic Obstructive Pulmonary Disease Knowledge Questionnaire (COPD-Q) [67]; Inhaled steroids in COPD patients' specific Knowledge

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scale [125]; COPD Patient Knowledge [124]; Are You an Asthma ACE? [71]; and Check Your Asthma "I.Q." [108]. The format and types of response options for these tools included true/false, yes/no, and multiple choice.

The second most assessed domain was the 'access' domain which was identified in 29 [66,73,75,77-80,82,84-86,90,91,94,96,97,99,100,102-104,107,109,111-115,122] tools and three [78,80,115] asthma tools assessed only that domain. None of the three tools had been validated. Tools that only assessed the 'access' domain asked questions on the barriers to accessing health information and services. The format and types of response options for these tools included yes/no and Likert-type scales.

The 'use' domain was assessed in 24 [69,73,74,76,77,79,81-86,93,94,96-98,100,106,109,110,112,113,118] tools, with four (2 asthma [81,98], 1 COPD [106], 1 asthma/COPD [93]) of them assessing only that domain. Three [81,93,106] out of the four tools had been validated. Tools that only assessed the 'use' domain were either scenario-type questions with an answer following a correct action (e.g., exacerbation onset and increasing medication/going to hospital) or medication adherence scales. The format and types of response options for these tools included yes/no, Likert-type scales, and open-ended responses.

The 'evaluate' domain was assessed in 20 [69,73,77,82-84,91,92,94,99,101,103-105,109,112,114,117,118,122] tools and two [92,105] COPD tools assessed only that domain. One [92] out of the two tools had been validated. Tools that only assessed the 'evaluate' domain asked questions on the ability to 'judge' or 'decide' upon a situation; for example, ability to judge how reliable or trustworthy a health source may be or deciding whether or not to follow instructions given a certain

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context (e.g., when symptoms are worsening). Likert-type scales were used for both tools that only assessed the 'evaluate' domain.

The ability to 'communicate' was the least assessed domain from the CCHL's 5-domain model, appearing in only 10 [72,77,79,82-84,90,97,102,104] out of the 65 tools. None of the 10 tools assessed only that domain. Tools that assessed the 'communicate' domain asked questions on experiences in communicating with a health care provider (e.g., doctor). The format and types of response options for these tools included true/false/not sure, yes/no, multiple choice, Likert-type scales, and open-ended responses.

Lastly, the 'numeracy' domain was applied in two tools: the Asthma Numeracy Questionnaire (ANQ) [95] and the HLS-EU-Q [94]. The ANQ assessed only 'numeracy' and examines understanding of numerical concepts such as instructions for self-management of asthma (e.g., peak flow readings and medication dosage). This tool has been validated. The format and types of response options for the ANQ included multiple choice and open-ended responses.

Figure 2.3 depicts a visual summary of the 65 measurement tools by the distribution of HL domains and disease.

Figure 2.3 Visual summary of 65 measurement tools by HL domains and disease



2.3.3 Reporting key components of validated tools

Thirty [62-69,76,77,81,83,86,87,90-95,97,99-101,106,107,110,115,118,126] out of the 65 tools identified in this review had been validated. A checklist for reporting key components of validated tools was developed by the study team based on factors that were considered important in the context of developing a comprehensive HL measurement tool. Validated tools were reviewed across components including: (1) application of a conceptual model/framework behind item development; (2) assessment of all five HL domains; and (3) detailed description of the scoring and validation processes (e.g., psychometric properties). Full and half points were assigned to each component (a total score of 3) depending on the availability and comprehensiveness. The MISS-21 [77] was the only tool that received a total score of 3. Eighteen [63,64,66-69,76,77,83,86,87,90,92,95,100,107,110,115] tools received a total score of 2 or more with the remaining 12 [62,65,81,91,93,94,97,99,101,106,118,126] fulfilling only one out of the three criteria. Among the 30 tools, 24 [63-69,76,77,83,86,87,90,92,94,95,99-101,107,110,115,118,126] of them had been developed based off a conceptual model/framework and only the MISS-21 assessed all five HL domains. All 30 tools provided detailed descriptions of scoring and validation procedures.

2.4 Discussion

This systematic review presents a comprehensive current review of HL measurement tools for asthma and COPD. On top of only assessing one or two HL domains, existing tools primarily focus on the ability of patients to comprehend and transmit health information and disregard the fact that this process requires at least two individuals co-constructing meaning when communicating [128,129]. It is important to understand that HL is more than a one-way street and that each of the domains requires the other individual in the equation: the health care provider.

In this review, I highlighted the paucity of literature in existing tools that assess a person's ability to communicate health information. Only 10 [72,77,79,82-84,90,97,102,104] out of the 65 tools were found to assess the 'communicate' domain (a total of 19 items). A potential reason for this could be because the review and search were based on print based tools whereas communication can also comprise of oral interactions. Moreover, communication is a complex phenomenon, potentially bridging written, visual, verbal, emotive, and auditory competencies, which make such contextually mediated interactions difficult to measure in the context of written materials. One technique used to measure communication in the context of HL is the 'teach-back' method [130] which is a technique health care providers use to assess whether a patient has understood important points covered in an education session. The 'teach-back' method works to enhance communication to restate what they just learned in their own words. Another mode of assessing communication is through open-ended responses; however, these types of questions

are often difficult to score and focuses too narrow on print and writing ability. Regardless, open-ended responses may offer more insights into the issues that are challenging a patient by allowing them to provide information as to why they have chosen a specific response [131]. Additionally, some of the identified tools were designed before the advent of the broader CCHL definition. Previous definitions had less emphasis on communication as a separate entity [27,28,132], possibly contributing to a bias towards understanding/content based items, which are more in keeping with the traditional HL definition. As a result, it came as no surprise that only two out of the 65 tools assessed all five HL domains. Consequently, the 'understand' domain was not un-expectedly the most frequently assessed domain found among the tools identified. The dominant focus on measuring understanding also confirmed my a priori assumption that measuring patient 'knowledge' was a common and attractive concept for both researchers and health care professionals in the field as compared to measuring the other HL domains.

The definition of HL has been dynamic over time and has evolved to include the five aforementioned domains. A new 'all inclusive' definition of HL was derived upon content analysis of 17 explicit definitions found in a systematic review on HL definitions and conceptual models conducted by Sørensen et al. [60]. One common attribute among the 17 definitions was the emphasis and focus on individual skills in accessing and understanding health information necessary to make appropriate decisions. During data extraction, agreement between reviewers in assigning HL domains to tool items was ensured via the methodology outlined above. Irrespective, it was frequently difficult to assign single, discreet HL domains to assessment items, as it is an inherently subjective process. In addition to a lack of clarity in respect to the domain being assessed in the item, many skills appeared to assess multiple domains simultaneously, making it difficult to assign a single unifying domain. This limitation was also mentioned by Haun and colleagues [53] in their descriptive summary of 51 HL measurement tools. The authors found that it was

difficult to place distinct parameters on the definition of HL, making it a challenge in determining what should or shouldn't be accepted as a HL tool. As such, significant gaps remain in the evaluation of HL tools due to the broad definition suggested by different researchers and organizations.

In regard to measurement tool characteristics, only a minority of tools reported on readability. Neither of the two [77,84] tools that assessed all five HL domains reported on readability. Multiple governing bodies have recommended a readability no higher than a 6th-8th grade education reading level [27,133], with the majority of reported readability complying with this. However, this finding is potentially biased by groups reporting readability being more likely to have designed tools with these constraints in mind. While it was not within the scope of this systematic review to assay unreported reading levels, this could potentially be a point of further investigation. Moreover, both [77,84] tools did not report on the time needed to administer the questionnaire. O'Neill et al. [134] showed in their systematic overview of selfadministered HL tools that less than half of the identified tools reported on the administration times which ranged from two to 70 minutes. It is important to note that interviewer-administered tools requiring more than 20 minutes to complete (despite being reliable, valid, and assessing all five HL domains) may be of limited value as they would be unacceptable in a clinical setting. Lastly, another important characteristic to consider is the concept of 'digital literacy' which is defined as a set of skills required in using digital technologies such as computers, tablets, and smartphones [135]. Existing HL tools could potentially be adapted to include the concept of digital literacy, for example, in the case of evaluating new technologies such as telehealth (e.g., application of telephone calls/short message service (SMS) in delivering education services or consultation). Although this is potentially an exciting new frontier, its assessment is beyond the scope of this thesis.

Finally, I found that less than half of the tools in this review had been validated and a little more than half of those tools had been developed based off a conceptual model/framework, assessed all five HL domains, and/or provided detailed descriptions on scoring and validation procedures. This finding was contrary to the three reviews led by Haun et al. [53], Altin et al. [136], and Kwan et al. [51] which identified a number of HL measurement tools validated by exploratory and confirmatory factor analysis, and the key types of validity such as content, construct, criterion, internal, and predictive validity. One reason for this could be due to the fact that this review focused on asthma- and COPD- specific HL tools, and also due to the inclusion of all five domains and numeracy in the search. By not limiting the search to the term 'health literacy' only, I was able to capture a wider range of HL measurement tools for asthma and COPD management.

2.5 Conclusions

There has been recent recognition that chronic disease management, which is currently the preferred strategy for addressing increasing rates of chronic diseases, can be improved through increasing the HL skills of patients as well as the communication skills of physicians and other HCPs [137]. A call to embrace the importance of HL in the context of chronic respiratory disease management has thus occurred in parallel with increased awareness of the importance of comprehensively measuring HL due to the fact that existing measurement tools do not optimally help researchers and clinicians identify the issues or important gaps of each domain. In conclusion, a number of HL tools related to asthma and COPD management have been developed but only two out of the 65 tools identified in this review captured the CCHL's 5-domain model of which one had been validated. The combination of domains was variable with more than half of the tools assessing the 'understand' domain and a limited number assessing the 'communicate' domain. In addition, less than half of the tools identified in this review had been validated.

A comprehensive and validated HL tool would therefore potentially be able to assist researchers and clinicians in measuring patients' HL as well as identify areas and skills where more work is needed for improvement. Such a measurement tool will likely lead to improvements in health outcomes and quality of life for patients with chronic respiratory disease and has the potential to be adapted for other chronic conditions.

Chapter 3: Bridging the gap: Key informants' perspectives on the barriers and solutions for chronic respiratory disease management

3.1 Introduction

The management of chronic diseases has shifted in recent times from the traditional provider-patient concept to a model in which patients play a more active role in their care in partnership with their health care providers [138]. Self-management describes the tasks that individuals must perform daily in living with their chronic condition. These tasks include medical management (e.g., medication adherence), lifestyle management (e.g., being able to recognize and manage symptoms/triggers), and psychological management (e.g., coping with emotions) [19-22]. Despite the recognition of the importance of disease management in maintaining chronic conditions, a majority of chronic respiratory disease patients, such as asthma and chronic obstructive pulmonary disease (COPD) patients, are not successfully involved in self-management practices as a result of socio-environmental and systemic factors, along with the lack of support from their care providers [139]. Other reasons for not following self-management practices also include forgetfulness, lack of perceived symptoms and benefits, fear of adverse effects, and nuisance or difficulty [140-142]. Although there is evidence of patients' willingness to become more involved in self-management [143], proper education and guidance from health care professionals (HCPs) are seldom offered and patients' understanding of their disease remains poor [144,145].

In order to effectively implement strategies directed at improving self-management practices, it is important to first become aware of the potential barriers that patients may be facing during self-management and gain insights into the current approaches/techniques that are used by HCPs. Globally, many studies have been conducted to investigate the perspectives of chronic respiratory disease patients

re their barriers and facilitators to involve in self-management practices [146-149]. However, there are only a few publications focusing on the elicitation of HCPs' views and perspectives of these patient barriers and the potential actions that can be taken in regard to such challenges [150-152]. In 2013, Roberts et al. [151] conducted a study among HCPs (consultants, general practitioners, specialists, and nurses) to investigate the barriers influencing self-management among asthma and COPD patients and found that lack of time during consultations and lack of resources (e.g., training and staff) were cited by many of the HCPs. Patient factors mentioned by HCPs included understanding such as literacy, cognition, and language barriers. Hillebregt et al. [150] also conducted a mixed methods exploration with COPD patients and their HCPs (respirologists, respiratory nurse specialists, general practitioners, nurse practitioners, and practice nurses) and highlighted organization of health care and consultation structure (e.g., consistency and collaboration between general practitioner and respirologist), engagement of patients in decision making, and patient-centered communication (e.g., not knowing how to communicate on the same level or connecting with patients) as issues relevant to effective self-management. Specific solutions to combat these issues and barriers were not examined in either studies.

Due to the lack of research eliciting HCPs' perspectives on patient barriers and solutions for selfmanagement, I conducted a qualitative study on data obtained from the 'Development and validation of Canadian health literacy measurement tool for chronic disease management' grant with two main objectives in mind:

• To assess key informants' (HCPs, researchers, and policymakers) viewpoints and thoughts on the major barriers that they perceived an asthma or COPD patient may be faced with in terms of self-management

 To identify any actions or solutions that the key informants have applied in clinical practice to overcome and address these challenges.

3.2 Methods

3.2.1 Study sample and recruitment

In-depth interviews were conducted with 45 key informants from Canada, the United States of America, the United Kingdom, and Australia between December 2015 and April 2016. The study participants included HCPs such as educators (e.g., respiratory educators, physiotherapists, and nurses) and clinicians (e.g., general practitioners, pharmacists, and respirologists); researchers; and policymakers involved in the care of patients with asthma and/or COPD and were recruited with the assistance from an advisory panel (AP) originally convened as part of a larger health literacy (HL) study. The key informants were introduced by the AP and were contacted by the project manager of the study through e-mail or by telephone for initial consent to be interviewed. Purposeful sampling was applied to ensure for maximum variation on key characteristics such as gender, profession, and geographic location. The intended sample size was a minimum of 24-30 key informants with an anticipation that the final number of interviews would vary depending on when theoretical saturation occurred (i.e., new themes ceased to develop).

3.2.2 Interview guide and data collection

A semi-structured interview guide was developed by the study team with further input and suggestions from the research collaborators and AP. The interview questions were primarily focused on identifying participants' perspectives and viewpoints on skills and abilities an asthma/COPD patient would need in to successfully manage their disease; barriers inhibiting successful management practices; challenges faced by both patients and key informants in terms of patient understanding and using health information; and the possible actions or solutions that have been taken to address the mentioned challenges. The interview guide that was developed for HCPs slightly differed from the interview guide developed for researchers and policymakers with an addition of four questions being asked from the researchers and policymakers. The specifics of these additional questions were on existing HL measurement tools and the development of a HL tool for asthma/COPD management, which were not analyzed in this study. A copy of the interview guide (HCPs and researchers/policymakers) can be found in Appendix D. The interview guide was pilot tested with 13 key informants for relevancy and appropriateness, and necessary modifications were applied before conducting the key informant interviews. An interview protocol was established prior to data collection to ensure consistency in conducting the interviews by the research team and evenness between the interviews as best as possible. The participants were interviewed in the English language by the project manager and myself and/or another research assistant either in-person, via telephone, or via Skype. Written or verbal consent was obtained before conduction of each interview. All interviews were digitally recorded and lasted approximately 30-45 minutes. The interviewers and I took notes during all interviews and these observations were reviewed together as a team at the end of each interview for reflection and debrief. The interview tapes were transcribed verbatim by a professional transcriptionist and myself, followed by a review for accuracy by two individual team members (project manager, research assistant or myself). The key informants did not receive any honorarium for completion of the interviews.

3.2.3 Data analysis

The 45 interviews were imported into the NVivo software (QSR International, version 10) for data management and analysis. To become familiar with the content before independently coding the raw data, I read and re-read the transcribed data several times before applying open coding and identifying text related to the two objectives of this study: (1) What do key informants (HCPs, researchers, and

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policymakers) perceive as barriers or problems that patients are experiencing in terms of selfmanagement?, and (2) What are some possible solutions that they suggest to address these issues? The analysis [153] was conducted by combining together different codes that were similar within the data to form a theme. Refinement of themes consisted of reviewing the coded data to ensure a coherent pattern and then considering the themes in relation to the entire data set. Transcripts were read again and further coding was conducted to ensure that no codes were missed in the earlier stages. Next, the themes were defined and named, and a detailed analysis was written for each individual theme. This was done by considering the 'story' within each individual theme as well as considering how it fit into the broader overall 'story' within the data [153]. Subthemes were also identified and vivid examples from the transcripts were extracted to illustrate the essence of the themes.

3.3 Results

In total, 45 male and female participants were interviewed from a list of 60 key informants initially contacted. Six key informants declined participation due to time conflicts, another six experts believed that their comments would not be helpful as they were not involved in the care of asthma or COPD patients, and three did not respond to the initial contact. Details and key characteristics of the 45 participants are provided in Table 3.1.

Table 3.1 Participants' descriptive details	(n=45)	
	Ν	(%)
Gender	I	ł
Female	30	(67)
Male	15	(33)
Profession		
Health care professional	28	(62)
Educator (e.g., respiratory educator,	16	(36)
physiotherapist, nurse)		
Clinician (e.g., general practitioner,	12	(27)
pharmacist, respirologist)		
Researcher	14	(31)
Policymaker	3	(7)
Geographic location		
Canada	40	(89)
The United States of America	3	(7)
The United Kingdom	1	(2)
Australia	1	(2)

The thematic analysis process resulted in a total of three key themes including 'What asthma and COPD patients should know about their disease', 'Perceived barriers to competent self-management', and 'Possible solutions and evaluation' constituting the 13 subthemes: 'Information overload', 'Inconsistent information received from HCPs', 'Time constraints', 'Medical jargon and reading level of materials', 'Beliefs and attitudes about treatment', 'Lack of patient involvement in developing educational materials', 'Memory problems and age', 'Take-home materials', 'Tailoring education', 'Follow-up visits', 'Promotion of questions', 'Better communication of HCPs and building relationships', and 'Teach-back method'.

3.3.1 What asthma and COPD patients should know about their disease?

The participants described topics and areas that they felt asthma and COPD patients should know about their disease. Table 3.2 presents a list of the knowledge gaps mentioned as a potential barriers to self-management.



3.3.2 Perceived barriers to competent self-management

3.3.2.1 Information overload

The quantity of information provided to patients from HCPs might contribute to treatment burden and overload for patients, was identified by the study participants as one of the most significant barriers to self-management. It was stated that patients are often overwhelmed with the amount or density of information that they are given and thus may struggle with achieving full comprehension of the material. As quoted by one of the educators [06/female] in the study: "... there is too much of information at once ... [consequently] they shut down, so we give them more stuff to do, they just don't bother, they just break down because there's too much treatment burden." Moreover, it was mentioned that patients who are very ill or experiencing shortness of breath are generally only thinking about how they are going to breathe comfortably in the moment and therefore, may not even bother listening to or applying the information into their self-management practices.

3.3.2.2 Inconsistent information received from HCPs

Another barrier reported by the participants was that patients are commonly given different information by different people, resulting in confusion about the accuracy of information, and this was an issue raised by an educator [01/female]: "patients are told one thing at the pharmacy or at their family doctor's and then told something different at the respirology clinic." The unique example given by the educator [01/female] was in relation to the recommendation of using a holding chamber while inhaling from the metered-dose inhalers (MDIs): "when I teach someone how to use an [MDI], I always recommend that they use this um (sic) holding device called a spacer or air chamber; well the patient was saying to me the family doctor told me that's for, little kids not for adults."

3.3.2.3 Time constraints

The study participants also mentioned perceived lack of time in clinical encounters to be a barrier to selfmanagement. A clinician [10/female] said: "we have to make a special effort to talk [the patient's] lingo and ask them if they have understood and then try to explain in the terms that they will understand, you know. So it's time consuming. So that's why it's not done." Insufficient time was stated as a barrier for both patient and professional due to the difficulty in harmonizing 'what patients wanted to know' with 'what HCPs needed to tell them'. Furthermore, time constraints were raised as barriers impeding clinicians' assessment of patient understanding which subsequently prevented them from being able to provide useful feedback.

3.3.2.4 Medical jargon and reading level of materials

One of the biggest barriers cited by the study participants was the use of medical jargon, either presented verbally or in written form during clinical encounters or provided as supplemental education aids. The participants mentioned that while the expected reading level for materials are supposed to be at a Grade 5 level, they found that this was generally not the case in their experience. Interestingly, a clinician [10/female] stated: "it's – we are the barrier because we don't make it available which is understood by lay people." However, another clinician [15/male] agreed with the principle but believed that overly simplifying information would result in loss of its purpose: "so there is always this push to be you know, more present to level of the sort of lay person ... the reality is that sometimes that's done to the point where you actually lose the key information, it's something that cannot be over simplified- it cannot be simplified to that point."

3.3.2.5 Beliefs and attitudes about treatment

Patients' beliefs and attitudes about treatment regimen prescribed for their chronic disease were described as a barrier to self-management. An educator [01/female] stated that patients' beliefs about the effectiveness of therapy are reasons for not using the given health information: "... so, they [patient] may have these preconceived ideas it's not going to work so then they don't follow the advice that they are given and so they don't give it a suitable enough length of time to try the therapy that the physician might want them to be on." The difficulty of changing such beliefs and attitudes was also mentioned by another educator [04/female]: "[patient] doesn't think they [inhaler] work ... so I explain it to him, I gave him a spacer. He's still not using it because he can't feel the medicine if he does that. He likes to feel it in his mouth to think he's getting it. I don't know how you change something like that but he's certainly not an isolated case." Additionally, the fear of becoming addicted to inhalers was mentioned as a common belief for reasons to not use medication.

3.3.2.6 Lack of patient involvement in developing educational materials

The participants reported an excess of health information and material designed solely by HCPs with none or minimal involvement of the people being served. It was mentioned that a co-operative effort was needed for the development of health information, as stated by a policymaker [03/female]: "find out what they [patients] want to know instead of what health care professionals think they need to know."

3.3.2.7 Memory problems and age

Another barrier cited by the participants was the difficulty in remembering and retaining information (e.g., forgetfulness or cognitive deficits) and this was indicated as a barrier mainly for COPD patients due to their age group. The study participants reported that older patients, specifically patients with dementia

or cognitive deficits, generally have difficulty comprehending new information that is given. This was mentioned by an educator [01/female]: "as people get older, as people age, you know issues with dementia right, that impacts their health because ... they can't remember what they're supposed to be taking, when they're supposed to be taking and that also makes it more difficult for them ... if they don't remember." In addition, age was also noted as a fundamental challenge to changing behaviour and long-term habits that have been embedded in older patients' lifestyle and routine activities for many years. The difficulty for older patients to form new habits was described by an educator [41/female]: "... the ability to think that they can make changes, I guess that's another part of ageing, is that it's difficult for them, 'I've done this all my life – I can't change now,' that kind of barrier."

Additional quotes in relation to 'Perceived barriers to competent self-management' are illustrated in Table 3.3.

Table 3.3 Quotes on perceived barriers to competent self-management

Information overload

"Sometimes that information overload if they [patient] come to see a respirologist, they've had a long day where they've done testing and they're tired and then they have to see me and talk to me and then see their doctor and we have to make new changes and I'll see them again and they're maybe kind of maxed out on information by the end of the day so again you're not retaining a lot." – educator [05/female]

Inconsistent information received from HCPs

"And when I say it, 'oh that's not right', 'well that's how the doctor or that's how the pharmacist showed me' and they [patient] trust that person more than me because they've only seen me once." – educator [04/female]

"I guess if the information makes sense is one thing and if it comes from different sources. If I'm telling them [patient] one thing and they can see on the Internet that it's saying pretty much the same thing and their doctor is saying something similar so that there's I guess consistency in the information that they're getting." – educator [41/female]

Time constraints

"Because it's hard to you know, have maybe anywhere from 15 to maybe 30 minutes with the patients, and often times they are going to come with their own idea of what they want to understand, but I also have to work with them on what the doctors want me to teach them and what to understand." – educator [19/female]

"I think time is the biggest factor, because as soon as you start, as soon as you start educating, you know sometimes you can have some sort of little topic that you want to ascertain on, it turns into an hour conversation right, because they have a lot of, the patient has a lot of questions about that or whatever, so again even providing that education, you can't just say yes I provided the education, it's like did they really understand right, and that takes time which the physicians certainly don't have, and yes so I think it gets lost a little bit." – educator [45/female]

Medical jargon and reading level of materials

"... A lot of our materials, I mean they are supposed to be at a grade 5 level. I'm not convinced that they always are so if we provide those with patients, I don't always think that they're actually being read or that information, they're comprehending that information, retaining that information." – educator [05/female]

"Oh yeah, well the basic barriers are that health related stuff tends to be presented in an overly complicated way." - clinician [15/male]

"I have heard of patients who are quite well educated, and this one person actually works in health care says that 'you know, I want health care professionals to stop using acronyms' when they describe their care." – researcher [35/male]

Beliefs and attitudes about treatment

"... They're [patient] able to understand the instructions and they can afford the medication but they're afraid of side effects and only will take it intermittently. And then they go through all of it, the medication works, they get better, and they decide because they're better they should stop, or they get better and they think that the benefits will wear off after time and they stop it, and then have a statement about side effects and about using medication and being labelled as having asthma or chronic disease that they don't want." – clinician [32/male]

"I know for a fact that there are lots of people who don't like taking the puffer because they are afraid of being addicted being to a puffer for the rest of their lives." – educator [42/male]

Lack of patient involvement in developing educational materials

"Involve them from the start. If you are planning to have a program for them, or a brochure for them specifically, it has to be culturally sensitive, language sensitive to their level, accessible, would not cost them anything, make it available, as free as possible, but involve them from the start, or involve any of the educators or relatives just so they own it." – policymaker [36/female]

"I guess, if it was written, developed in collaboration with the patients, these days we talk about including patients in developing the materials so if there was a patient voice in the development of the materials, I think that would make sense to the other patients who are using it and hopefully they will use that information and can see the outcomes." – educator [16/female]

Memory problems and age

"... You know we've had people who have memory issues like I, I have one patient in particular who I see her pretty much every time she comes to the clinic because she can't remember what I told her, yeah and so like you teach them how to use their inhaler and they go home and they don't remember." – educator [01/female]

"So when we have older patients specifically patients with dementia or with cognitive issues, they may not comprehend the information because the information we are providing at this time of life may be all new to them." – educator [16/female]

"I think it's more difficult to make behavioural changes, lifestyle changes, especially when you are in your 70s and 80s, and it's just the fact that even if they are doing well when they are sick, it's that much harder to get back into it." – educator [41/female]

3.3.3 Possible solutions and evaluation

3.3.3.1 Take-home materials

Providing patients with relevant information (e.g., pamphlets, handouts, and videos) which has been developed in plain language to take home after an education session was highlighted as a possible solution to address perceived self-management barriers. A clinician [11/female] described the importance of providing written materials and reinforcing this information at future visits: "... you know ideally every patient diagnosed with a condition on day 1 would receive that written information, and that written information would be reinforced at every visit." Another clinician [33/male] suggested the application of videos to aid patient understanding: "... that might help because that doesn't – that may not require reading ... And for many patients that might be a better way to convey the information. And the other advantage is that if there is something they have to hear twice or three times, they can rewind the video and go back to it and hear it two or three times until they understand it."

3.3.3.1 Tailoring education

The participants stated that delivering health information that relates to how the patient is feeling and what is happening in their everyday life would better help them apply this information in practice. It was noted that education should be personalized and that people would be willing to change their behaviour when they see a benefit to it. When describing ways to make information more personal, a clinician [10/female] quoted: "making it personal using their own example or their own health status or their own risk factors, or their own events that happened to them and implying that health information then it becomes more personal. It's their story and not somebody else, something happens to somewhere else."

3.3.3.1 Follow-up visits

The participants stated that information for patients who only come to the hospital once or twice is usually crammed into a session. As a result, follow-up visits were reported as a possible solution to combat the time restraints, and burden of information in a single appointment. Furthermore, follow-up visits and calls were described as incentives for patients to continue their self-management practices, as stated by an educator [7/female]: "... if they [patient] know that we're going to be checking in on them, there might be hopefully a more of an incentive to continue with the exercises or the deep breathing techniques that are taught ... If they knew that was it, nobody was ever going to check in with them again, I think that a majority of people would just not do it."

3.3.3.1 Promotion of questions

Encouraging patients to ask questions after an education session or appointment was also mentioned as a way to assist patients in self-management. The participants noted that at times, it is difficult to truly ascertain whether a topic was understood clearly by the patient without specifically prompting them. In addition, the suggestion that patients ask questions from HCPs may also dismiss the power imbalance between HCPs and patient, as stated by a researcher [02/female]: "so you need to show them [patient] to help them become comfortable ... 'Do not be ashamed to ask me questions. I absolutely need you to ask me questions' ... So we need to dismiss the image that the person, the teacher, or the educator is someone who is kind of a god, goddess, that you cannot ask them."

3.3.3.1 Better communication by HCPs and building relationships

The improvement of HCPs' communication skills in addition to better patient-physician interactions were suggested as solutions to enhance patient self-management. There was agreement among the
participants that HCPs should communicate in ways that allow the patient to competently understand and use health information. A clinician [11/female] stated: "and also, one thing is also that physicians, I speak for myself too, aren't necessarily the greatest at communicating information in a way that is easily understood, ... because patients might be able to more easily understand what you are saying if you're able to explain it in a better way." It was mentioned by an educator [05/female] that building relationships and trust with patients was vital: "that's kind of what, ... what I've learned is that at the end of the day we really do work hard on a daily basis to build relationships with people and get to know people and meet them where they're at, because that's when they're gonna (sic) be the most receptive to the information that we have or the resources that we have."

3.3.3.1 Teach-back method

The teach-back method was the most common method used among the participants for assessing patient understanding. Similar to encouraging patients to ask questions, the study participants indicated that the teach-back method was also a way to determine whether patients heard and understood the information that was taught. This technique was described as being useful by an educator [05/female]: "... and if they [patient] aren't able to tell me or explain to me they've understood the information they've received, that they can apply it to a future situation then that would kinda (sic) be a red flag and I would want to review that information again." A clinician [12/female] also confirmed this: "... you have to ask them to repeat back to you how it's done, or to perform to you how it's done. But you have to evaluate, test them, to see whether they actually understood you or not."

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Table 3.4 contains quotes made by the participants on 'Possible solutions and evaluation' for perceived self-management barriers.

Table 3.4 Quotes on possible solutions and evaluation for perceived self-management barriers

Take-home materials

"Yep (sic), ok yep (sic) so basically meeting with an individual who can explain to them [patient] and provide them with like subsequent materials that they can take home." – educator [01/female]

"Also mentioned, we do try to provide handouts as well so when people come in for education with our team we may be talking for half an hour forty-five minutes but we try to follow up with a variety of simple handouts, things that are already established ... and then also by them being able to take it away they have something to reflect back on to so if it maybe didn't fully make sense what I said, they now have something that they can read themselves over again to the point where it hopefully does make sense that they weren't comfortable asking to begin with." – educator [07/female]

Tailoring education

"Being able to provide messages that are about things that people actually care about or being able to help them understand why what you are talking about is important to them, so personalizing information." – policymaker [03/female]

"The factors are how personalized the information is. There is information and then there is your patient or the person whom you want that to be used by. So how personalizing you made that message, that is really, really, important and we know that from other research that if you make it personalized then it is more likely to be taken up." – clinician [10/female]

"Yeah, cause people are only interested in their condition, they are not interested in generic (sic), so the best way to increase the skills is to say here's some information about your condition." – clinician [12/female]

Follow-up visits

"I just might have to follow up a couple of more times with trying to get them to go to their doctor and ask for an action plan but they won't have it written to remind them." – educator [04/female]

"Follow-up, continuous follow-up." – educator [06/female]

Promotion of questions

"... And then getting them to write down any questions that they have in preparation of their appointment, and generally to keep a document about their progress in their own journals themselves." – educator [06/female]

"Just the body language and then asking questions, pausing in between and asking questions if they have understood or if they have any questions and if they are not asking any counter questions, then you have maybe some clue that they may not be understanding what you are saying." – clinician [10/female]

Better communication of HCPs and building relationships

"Oh, yeah, I think there is (sic) ways that health care professionals can communicate, you know, the expertise of the patient and their expertise and how they work together for collaboration. So yeah, I think there is definitely ways to do that." – policymaker [03/female]

"I think the first thing is the communication skills and taking time to let them understand it and be able to ask questions in a nonthreatening environment because if patients feel like they are being rushed by a health care professional or whoever is providing them with the information, they are not going to ask questions and they are therefore less likely to actually understand it and therefore less likely to do the right thing or follow the instructions. So giving the right amount of time for communication and not making them feel rushed is really important." – educator [44/female]

Teach-back method

"... And I think if providers – if health care professionals don't ask people to say back what they understood, that you can teach patients that at the end of the visit to say, you know, I would just like to go over to summarize. I would just like to go over what we did today." – policymaker [03/female]

3.4 Discussion

Existing research has primarily found patient barriers with self-management to be largely influenced by psychosocial factors (e.g., depression and stress), poor communication with care providers, and lack of support from family members and friends [147,149,150,154]. Nevertheless, the majority of these findings are derived from patients' perspectives, and typically do not take into consideration the viewpoints of HCPs who work with the target population. The aim of this qualitative investigation was to better understand key informants' (e.g., HCPs, researchers, and policymakers) perspectives on the perceived barriers an asthma/COPD patient may be faced with in terms of self-management practices and the recommended solutions to overcome such challenges. Thematic analysis of the 45 interviews resulted in seven subthemes stemming from the key theme 'Perceived barriers to competent self-management' including 'Information overload'; 'Inconsistent information received from HCPs'; 'Time constraints'; 'Medical jargon and reading level of materials'; 'Beliefs and attitudes about treatment'; 'Lack of patient involvement in developing educational materials'; and 'Memory problems and age' and six subthemes: 'Take-home materials'; 'Tailoring education'; 'Follow-up visits'; 'Promotion of questions'; 'Better communication of HCPs and building relationships'; and 'Teach-back method' from the 'Possible solutions and evaluation' key theme. This study is the first of its kind to explore the perspectives of key informants (HCPs, researchers, and policymakers) on perceived asthma/COPD patient self-management barriers and the possible solutions.

One of the barriers to competent self-management as reported by the participants was limited time to provide education and this finding was consistent with studies conducted by Roberts et al. [151] and Young and colleagues [152] on the lived experiences of nurses' and allied health professionals' (AHPs) supporting COPD self-management and their perceptions of the challenges in providing such care.

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Similarly, the participants from this study also identified lack of time impeding the ability to prioritize work tasks (e.g., covering required information but also having enough time to address any other issues that may arise). Although this issue appears to be a systemic factor that would require changes at a systemand policy-level, two solutions to resolve this barrier were suggested by the key informants: (1) the option of conducting more follow-up visits as well as providing take-home materials after an education session; and (2) improvements in HCPs' communication skills in terms of conciseness and reduced difficulty of information presented to patients. These strategies may minimize the event of a high volume of health information being condensed to fit the allocated time for one session. A common concern for patients is the fact that clinicians do not often engage in asking questions from patients and are seldom inclined to hear the patient's perspective [155]. Successful patient-physician interaction entails developing interpersonal relationships, facilitation of knowledge transfer through speaking and listening, and involving patients in the decision making process in regard to their care [156]. Additionally, old age and cognitive deficits, resulting in patients feeling less motivated and unwilling to change or learn new habits, were also mentioned by the study participants as challenges hindering optimal self-management. The solution proposed for this challenge was to meet with patients more often in order to provide them the opportunity to be reintroduced or learn more about a previously discussed topic. It is interesting to note that the nurses and AHPs in the study conducted by Young et al. [152] felt that their professional knowledge and skills alone were sufficient in supporting patient self-management. In contrast, my qualitative data did not replicate this finding and in its place, cited HCPs' concerns re their communication skills. Young's study [152] also described language and cultural barriers as challenges making selfmanagement more difficult and while this was not a main finding in this study, a few key informants commented on this within the subthemes 'Beliefs and attitudes about treatment' and 'Lack of patient involvement in developing educational materials'. A possible solution for this which was briefly touched

on during the interviews, was the idea of including 'navigators' within the health care system, to help patients with identifying the needed information and services. This 'navigator' could range from a health care professional to a peer patient or a family member.

The most striking finding of this study is the fact that many of the perceived barriers to self-management mentioned by the participants can be classified as systemic barriers indicating a problem with the health care delivery system and patient-physician interaction. At times, patient barriers to self-management are often thought of as a 'patient problem' and not a system or policy issue. I believe that a possible reason for this may be due to the fact that the study sample included a broad range of key informants (such as researchers and policymakers in addition to clinical personnel), enhancing relevance to systemic health care issues. The participants had first-hand encounters with asthma/COPD patients either in treatment, in education, in research, or in policy, and recommended potential solutions based on their personal experiences with patients. The solutions proposed in this study confirm that self-management is a concept not only consisting of treatment and treatment adherence, but also involving the establishment of relationships and communication building. 'Humanomics', as termed by FitzGerald & Poureslami [157], signifies the acknowledgement of behavioural perspectives (e.g., HL and numeracy) on self-management. In their commentary, they emphasized the need to provide information at the level of the recipient and restated the importance of involving patients in the development of tailored interventions. The authors recognize that proper communication with patients is fundamental and that other aspects such as cultural factors and HL exist in the ability of patients to successfully manage their disease, and have conducted several studies involving Punjabi, Cantonese and Mandarin asthma/COPD patients in material development [158,159].

3.5 Conclusions

In summary, self-management is a combined effort achieved only through engagement of HCPs, patients, and the system. Active facilitation of self-management practices require complete understanding of the patient, their needs, barriers, and what solutions could be applicable to address the challenges they may face. Although many of the barriers noted by the participants were system-related factors such as time constraints and inconsistent information received from HCPs, the key informants also provided insights into how they effectively countered these problems. Therefore, it is believed that key informants (HCPs, researchers, and policymakers) recognize the need for their responsibility in successful patient self-management. Future directions could include assessing the similarities and differences between patients' and key informants' perspectives around self-management barriers and facilitators with the potential to develop a conceptual concept of HL and its effect on asthma/COPD management.

Chapter 4: Conclusions

4.1 Overview of the two studies

This thesis consisted of two separate studies: (1) a systematic review examining the literature on health literacy (HL) measurement tools related to asthma/chronic obstructive pulmonary disease (COPD) management and their characteristics such as the distribution of the five HL domains as defined by the Calgary Charter on Health Literacy in addition to the underlying content, number of items, types of response options, scoring, readability, and administration; and (2) a qualitative analysis looking into the perspectives of key informants (e.g., health care professionals (HCPs), researchers, and policymakers) who are involved in the care of patients with asthma and/or COPD on the perceived patient barriers to competent self-management and the possible solutions to overcome these barriers. The main aim of my research was to incorporate both sides of the HL equation (patients' ability and key informants' perspectives) into the investigation of the role of HL in chronic respiratory disease management.

Among the 65 HL measurement tools identified in the systematic review, the majority of them (n=49) [62-77,79,83,84-90,94,96,99,101,103,104,106-116] were found to assess asthma/COPD patients' 'understanding' or 'knowledge' of health information with a limited number of tools assessing the ability to 'communicate' health information (n=10) [72,77,79,82-84,90,97,102,104]. Only two [77,84] out of the 65 tools assessed all five domains of HL and less than half of them (n=30) [62-69,76,77,81,83,86,87,90-95,97,99-101,106,107,110,115,118,127] have been validated. In the qualitative analysis, seven key barriers stemmed from the theme 'Perceived barriers to competent self-management' including 'Information overload'; 'Inconsistent information received from HCPs'; 'Time constraints'; 'Medical jargon and reading level of materials'; 'Beliefs and attitudes about treatment'; 'Lack of patient involvement in developing educational materials'; and 'Memory problems and age' and six solutions: 'Take-home materials'; 'Tailoring education'; 'Follow-up visits'; 'Promotion of questions'; 'Better communication of HCPs and building relationships'; and 'Teach-back method' emerged from the 'Possible solutions and evaluation' key theme during thematic analysis of the 45 interviews. The findings from the systematic review were verified with chapter 3 as the key themes and subthemes acknowledged limitations with the 'communicate' domain. Chapter 2 highlighted the scarcity of HL measurement tools that assessed a patient's ability to communicate health information, possibly due to the complex phenomenon of communication requiring at least two individuals in the process, and chapter 3 identified self-management barriers (e.g., information overload, inconsistent information received from HCPs) and solutions (e.g., promotion of questions, better communication of HCPs and building relationships) surrounding the theme of communication and patient understanding in the context of self-management. The 'teach-back' method implies that the person receiving the health information restate what they have just learned in their own words and enhances the communication between the patient and the provider (person providing the information).

4.2 Strengths and limitations

A major strength of my thesis work is the focus on both perspectives (patients and key informants involved in the care of patients with asthma and/or COPD). In chapter 2, a systematic review was completed on existing HL tools related to asthma/COPD management and their distribution of domains in terms of a patient's ability to access, understand, evaluate, communicate, and use health information to make informed decisions. Then, in chapter 3, I conducted a qualitative analysis looking at the insights of key informants (e.g., HCPs, researchers, and policymakers) on their firsthand experiences of asthma/COPD patients' barriers and obstacles to self-management and their suggestions to overcome these issues in practice. Consideration of both sides of the self-management equation ensured that the information collected on HL was comprehensive and inclusive of all key players in the health care interaction. The systematic review also has strengths. All five HL domains in addition to numeracy were included in the search strategy which enabled me to acquire an abundance of HL tools related to asthma/COPD management. In addition, study selection and data extraction were carried out by two reviewers (and a third reviewer when necessary) at all times to minimize bias. One of the strengths of the qualitative study is the variation of genders, professions, and geographic locations in the study sample. The study sample comprised of researchers and policymakers as well as HCPs which enriched the quality of the data, providing perspectives into policy and the health care system.

Regardless, this thesis work has its limitations as well. The search in the systematic review was limited to English language publications only and this may have resulted in loss of quality and/or relevant information. Furthermore, tools that assessed the HL of health care providers, caregivers, or the general population were excluded from this review; however, HL extends beyond the individual and requires understanding of all key players involved. Also, some of the tools included in the review were selfadministered and most of them were self-evaluation type questions which may be of concern due to reasons such as tendency to over evaluate self ability and skipping or not answering all questions. In the qualitative study, the main objective was to assess key informants' perspectives on patient selfmanagement and therefore, a limitation would be the absence of patients' ideas in the findings. A future study looking at the comparisons between patients' and key informants' perspectives in regard to the barriers and solutions for self-management practices is ideal. In terms of the study sample, purposeful sampling resulted in twice as many females as males and also a limited number of policymakers. An additional number of policymakers may provide a better idea re key informants' perspectives on perceived patient barriers and solutions on a large scale. Moreover, analysis of data between the different professions was not conducted. This could be a point of further research to determine if different themes and subthemes may occur across the different professions. Nonetheless, I believe that both studies contributed to the knowledge on the role of HL from the outlook of patients and key informants' understanding on the real needs of asthma/COPD patients in terms of disease management.

4.3 Implications of research findings

Being able to access, understand, evaluate, communicate, and use health information to make informed decisions for one's health is fundamental for the self-management of chronic diseases. My thesis work presents a comprehensive and coherent view of HL and its role in asthma/COPD management. The studies presented in this thesis provide significant contributions to both research and clinical practice by recognizing the shortages and deficiencies with the definition of HL, its measurement, and identifying the possible solutions to counter patient barriers for better self-management. In chapter 2, it is evident that attention needs to be focused on clearly defining HL and its domains. Although the majority of the identified tools assessed patients' 'understanding', it is not clear which of the HL domains are most salient. More work needs to be done towards conceptualizing a unified definition of HL and reframing the CCHL based on the insights developed from this work (e.g., including other domains such as digital literacies, structural competency, efficacy) in order to be able to successfully develop and evaluate a HL measurement tool for asthma/COPD management. The distribution of the five HL domains in a measurement tool also needs to be further studied; barring any evidence suggesting that some domains may be more important than others. A comprehensive and validated HL measurement tool would be able to identify the more important HL domains once used in a target population. The Medical Interview

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Satisfaction Scale (MISS-21) [77] and the 1600 REALISE ASIA Asthma Patient Survey Questionnaire [84] are two measurement tools identified in the review as containing assessment of all five HL domains. In spite of this, neither of these tools were designed with the explicit purpose of assessing HL and hence, show a disproportionate distribution of the five domains among the items. Furthermore, both tools are limited in that they do not assess the actual ability of patients to actively participate in their medical care (i.e., performance-based assessment of the five domains); do not address the role of the HCP in communication; nor provide a mechanism of feedback to HCPs in regard to which HL domains or skills are deficient. The development of an all-inclusive and validated HL measurement tool for asthma/COPD management will not only assist researchers and clinicians to accurate measure patients' HL but also capture the specific areas and skills where more work or attention may be needed.

In chapter 3, I provided new insights into the understanding of patient barriers and solutions through the lens of key informants (e.g., HCPs, researchers, and policymakers). The subthemes related to both the barriers and solutions from the qualitative analysis illustrate a need for change within the health care system in the five HL domains. The findings show that improvements are required in terms of the interactions (mainly communication) between patients and HCPs in order to successfully engage patients in the use of self-management practices. Practice implications could include identifying and training clinician leaders as so called 'agents of change' [160] from a self-management perspective. These leaders could both disseminate education to relevant care providers, and ensure ongoing quality at a practice level. Moreover, improvements in HCPs' communication skills can be established by educating early career physicians on the concept of HL and its five domains to incorporate them early in the process. Education that is provided to patients, either verbally or in writing, must also be tailored to the individual's situation (e.g., lifestyle and cultural background) to ensure applicability and use. Other opportunities for

this work may include the integration of patients in decision making and involvement of family members not only in the delivery of care but also from start with the development of educational materials. In addition, insights and engagement of key stakeholders (e.g., patients, HCPs, researchers, and policymakers) is critical to ensure practicality of a HL measurement tool for both the clinical and research setting.

4.4 Concluding remarks

This research is part of a multi centre project funded by the Canadian Institutes of Health Research (CIHR) aiming to develop and validate a new HL measurement tool to optimize asthma/COPD management. The findings from the systematic review along with the qualitative data collected from key informant interviews will facilitate the development of a comprehensive HL respiratory-specific tool, a new assessment standard if you will. An improved and enhanced HL measurement tool that can accurately assess the HL of patients as well as identify the weaknesses and deficiencies between each of the domains in patients will be able to suggest better interventions that can be targeted for those specific domains and to improve the management of chronic diseases. In addition to facilitating the development of the tool, the findings from chapter 3 convey important clinical and policy implications. It is commonly believed that the role of HL should be primarily concentrated on the ability of patients; however, my qualitative analysis showed that the interviewed key informants acknowledge the shortcomings to competent self-management on their part and on the responsibility of the system. Therefore, it is suggested that HL researchers and health care programs investigate the possible implementations of new strategies for chronic respiratory disease management with a specific emphasis on the concept of 'communication'.

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Appendices

Appendix A: MEDLINE and Embase (Ovid) search

Search was executed on: Nov. 26, 2015

Database: Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) <1946 to Present>

Search Strategy:

- 1 health literacy/ (2464)
- 2 health literacy.tw. (3573)
- 3 or/1-2 (4569)
- 4 Health/ (19325)

5 communication/ or access to information/ or communication barriers/ or health communication/ or information seeking behavior/ (78162)

- 6 information literacy/ (129)
- 7 literacy.tw. (10430)
- 8 ((access\$ or seek\$) adj5 information).tw. (15719)
- 9 (literac\$ adj5 information).tw. (614)
- 10 or/5-9 (101597)
- 11 4 and 10 (807)
- 12 Health Knowledge, Attitudes, Practice/ (81606)
- 13 health education/ (54598)
- 14 consumer health information/ (2311)
- 15 patient education as topic/ (74445)
- 16 or/11-15 (197014)
- 17 Questionnaires/ (337065)
- 18 Educational Measurement/ (30218)
- 19 Psychometrics/ (59513)

20 (measures or measurement or test? or assessment or screen or screening or instrument).tw. (3003306)

- 21 or/17-20 (3245730)
- 22 16 and 21 (66008)
- 23 exp Asthma/ (112972)

24 lung diseases, obstructive/ or bronchitis/ or bronchiolitis/ or bronchitis, chronic/ or pulmonary disease, chronic obstructive/ or pulmonary emphysema/ (76726)

- 25 23 or 24 (180011)
- 26 16 and 21 and 25 (1528)

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27 3 and 21 and 25 (55)
28 26 or 27 (1554)
29 limit 28 to yr="1985 -Current" (1526)
30 limit 29 to English language (1341)
31 comment/ or editorial/ or letter/ or news/ (1686865)
32 30 not 31 (1326)
33 limit 32 to "review articles" (117)
34 limit 32 to systematic reviews (70)
35 33 or 34 (150) [Reviews]
36 32 not 35 (1176)
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Search was executed on: July 8, 2016

Results:

- 92 90 not 91 (1808)
- 95 limit 90 to (conference paper or conference proceeding or "conference review") (38)

Database: Embase <1980 to 2016 July 08> Search Strategy:

- 1 health literacy/ (4865)
- 2 health literacy.tw. (5028)
- 3 1 or 2 (6749)
- 4 access to information/ (15491)
- 5 help seeking behavior/ (6654)
- 6 (help adj2 behavio?r).tw. (1557)
- 7 ((seek\$ or access\$) adj4 information).tw. (17789)
- 8 information seeking/ (1649)
- 9 information retrieval/ (27225)
- 10 or/4-9 [Assessing health info] (65097)
- 11 medication understanding/ (1)
- 12 comprehension/ (21961)
- 13 drug self administration/ (9070)
- 14 knowledge/ (25865)
- 15 language ability/ (9352)
- 16 reading/ (43242)
- 17 ((consumer? or patient) adj3 assessment).tw. (15733)
- 18 or/11-17 [Understanding] (118956)

- 19 communication skill/ (8805)
- 20 interpersonal communication/ (136542)
- 21 doctor patient relation/ (86091)
- 22 (communicat\$ adj5 information).tw. (11952)
- 23 or/19-22 [Communication] (221559)
- 24 decision making/ (168731)
- 25 consumer health information/ (2858)
- 26 awareness/ (40495)
- 27 health care access/ (44348)
- 28 (evaluat\$ adj5 information).tw. (15308)
- 29 or/24-28 [Evaluation] (266860)
- 30 patient compliance/ (110554)
- 31 ("use" adj3 information).tw. (20250)
- 32 ((patient? or consumer?) adj5 (knowledge or practice or judgement or skills?)).tw. (76410)
- 33 patient assessment/ (25488)
- 34 or/30-33 [using information] (228156)
- 35 health behavior/ (51230)
- 36 health education/ (83008)
- 37 drug information/ or medical information/ (79749)
- 38 patient education/ (95416)
- 39 attitude to health/ (90183)
- 40 health belief/ (7159)
- 41 mass communication/ (12716)
- 42 information dissemination/ (16571)
- 43 patient preference/ (9587)
- 44 patient information/ (21672)
- 45 attitude to illness/ (3852)
- 46 calculation/ (75666)
- 47 functional status assessment/ (784)
- 48 functional status assessment/ (784)
- 49 functional assessment/ (53593)
- 50 or/35-49 [General] (547879)
- 51 or/3,10,18,23,29,50 (1098284)
- 52 questionnaire/ (484168)
- 53 screening/ (146718)
- 54 psychometry/ (49155)
- 55 scoring system/ (201180)
- 56 criterion related validity/ or validity/ (37333)
- 57 reliability/ or internal consistency/ or test retest reliability/ (120755)
- 58 validation process/ (84885)
- 59 reproducibility/ (170840)
- 60 health survey/ (168594)

- 61 content validity/ (4001)
- 62 construct validity/ (8354)
- 63 rating scale/ (95692)
- 64 screening test/ (55112)
- 65 measurement/ (87195)
- 66 validation study/ (57691)
- 67 "assessment of humans"/ (7123)
- 68 "named inventories, questionnaires and rating scales"/ (14527)
- 69 instrument/ (23321)
- 70 principal component analysis/ (28372)
- 71 factorial analysis/ (30589)
- 72 "sensitivity and specificity"/ (250234)
- 73 face validity/ (2064)
- 74 Likert scale/ (6734)
- 75 criterion related validity/ (1510)
- 76 self report/ (83687)
- 77 self evaluation/ (23997)
- 78 (psychometric or item generation or short form or internal consistency).tw. (75904)
- 79 or/52-78 (1800131)
- 80 51 and 79 (210176)
- 81 exp *asthma/ (138861)
- 82 *chronic obstructive lung disease/ or *obstructive airway disease/ (47577)
- 83 *pulmonary rehabilitation/ (1862)
- 84 *lung emphysema/ or *emphysema/ (14402)
- 85 or/81-84 (196353)
- 86 51 and 79 and 85 (2560)
- 87 limit 86 to yr="1985 -Current" (2558)
- 88 limit 87 to English language (2345)
- 89 limit 88 to (editorial or letter or note) (144)
- 90 88 not 89 (2201)
- 91 limit 90 to (conference abstract or conference paper or conference proceeding or "conference review") (393)
- 92 90 not 91 (1808)
- 93 MEDLINE.cr. (10098786)
- 94 92 not 93 (1552)
- 95 limit 90 to (conference paper or conference proceeding or "conference review") (38)

Appendix B: Data extraction forms

Health Literacy Data Extraction Fields for Tools

Tool ID	
Name of tool	
Name of person extracting data	
Year of publication	
Where was it developed (country)	
Who developed the tool	
Purpose of the tool	
Target population for which the tool was	
designed (gender, age, level of education,	
chronic disease)	
Versions of the tool (e.g., short form, revised)	
Who administers the tool (e.g., self-	
administered, interviewer-administered)	
Total number of items	
Sections (topics) in the tool	
Number of items in Access domain	
Number of items in Understand domain	
Number of items in Evaluate domain	
Number of items in Communicate domain	
Number of items in Use domain	
Number of numeracy items	
Number of items not measuring health literacy	
How is the tool scored	
Strengths of the tool	
Weaknesses of the tool	
Date of completion of data extraction	
Notes	

Tool Items and their Domains

(Completed by two reviewers independently if domains not stipulated)

Data Extractor	Tool ID	Item #	HL Domain	Notes
			Access	
			Understand	
			Evaluate	

	Communicate	
	Use	
	Numeracy	
	Not HL	

Health Literacy Data Extraction Fields for Studies

Name of person extracting data	
Tool ID	
Authors	
Title of paper	
Year of publication	
Published or grey literature?	
Name of journal (if applicable)	
Geographic location of development/validation	
Is this paper a development and/or validation study?	
Purpose of the paper/study (include hypotheses being	
tested)	
Study design	
How was the sample obtained?	
Description of the sample (gender, age, level of	
education, chronic disease)	
Were patients and/or caregivers asked to provide input	
on content/face validity?	
Which version of the tool is being developed/validated	
Underlying constructs of the tool	
Reported time to participants to complete the tool	
Readability - scale used and result	
Strengths of the study	
Weaknesses of the study	
Date of completion of data extraction	
Notes	

Appendix C: Checklist for reporting key components of validated tools

Tool name	Conceptual model/framework	Five HL domains	Validation processes	Total score
Asthma General Knowledge Questionnaire for Adults with Asthma [62]	0	0	1	1
The Lung Information Needs Questionnaire (LINQ) [86]	1	0	1	2
12-Item Consumer Asthma Knowledge Questionnaire (Cq) with a True/False Response [63]	1	0	1	2
Asthma Self-Management Questionnaire (ASMQ) [64]	1	0	1	2
Asthma Knowledge Questionnaire [68]	1	0	1	2
Asthma self-management knowledge questionnaire [65]	1	0	0.5	1.5
The Knowledge, Attitude, and Self-Efficacy Asthma Questionnaire (KASE-AQ) [109]	1	0	1	2
Bristol COPD Knowledge Questionnaire (BCKQ) [87]	1	0	1	2
Asthma Numeracy Questionnaire (ANQ) [95]	1	0	1	2
Patient-Clinician Communication [97]	0	0	1	1
Understanding COPD Questionnaire (UCOPD) [66]	1	0	1	2
Use of MDIs in Hospital Environments [99]	1	0	0.5	1.5
Asthma Behaviour Change (ABC) [69]	1	0	1	2
Health Literacy Screening Questions Assessment [107]	1	0	1	2
Knowledge and Attitudes of Asthma [76]	1	0	1	2
Patient Asthma Concerns Tool (PACT) [100]	1	0	1	2
Medical Interview Satisfaction Scale (MISS-21) [77]	1	1	0.5	2.5
Quality of Communication Questionnaire (QoC) [90]	1	0	1	2
Medication Adherence Report Scale (MARS-5) [93]	0	0	0.5	0.5
Assessment of Care for Chronic Conditions [91]	0	0	1	1

Asthma Opinion Survey [114]	1	0	1	2
Seattle Obstructive Lung Disease Questionnaire (SOLDQ) [92]	1	0	1	2
Medication and Inhaler Adherence Scale [81]	0	0	1	1
Asthma Knowledge Questionnaire [101]	1	0	0.5	1.5
Judgement Skills Scale [83]	1	0	1	2
COPD Self-Management Interview (COPD-SMI) [106]	0	0	1	1
Knowledge and Attitude Assessment [117]	1	0	0.5	1.5
Evaluation of Pictorial COPD Action Plan [126]	0.5	0	0.5	1
European Health Literacy Survey Questionnaire (HLS-EU-Q) [94]	1	0	0.5	1.5
Chronic Obstructive Pulmonary Disease Knowledge Questionnaire (COPD-Q) [67]	1	0	1	2

Appendix D: Qualitative interview guide

- 1. Can you provide some examples of barriers to chronic disease management that are imposed on patients due to limited knowledge and low health literacy skills?
- 2. As a health care provider/professional, what are some of the unique challenges that your patients/clients may have come across in accessing health information?
- 3. Were there instances where your patients/clients had difficulty in understanding the information you provided?
- 4. How do you know when your patients/clients did not understand the health information given, or when did you know you had to explain or elaborate on concepts?
- 5. What would help to make it easier for your patients/clients to understand the information given to them in regards to their health and health literacy?
- 6. Can you identify some barriers that inhibit clear communication of health information to patients /clients with limited literacy skills in regards to chronic disease management?
- 7. In your opinion, what factors would help in making your patients/clients confident about the validity and relevancy of the information that they receive?
- 8. In your opinion, what would promote your patients/clients to use the information they have received about asthma/COPD in their routine life?
- 9. What are the challenges you may face in providing services to diverse patient populations? i.e., differences in regards to culture, ethnic background, gender, age, education, and etc.
- 10. What are some actions that you normally take to address these challenges?
- 11. What are some additional things that you think can be done to improve care/services?