Promoting Health Education and Behavior Change for Chronic Lung Disease: Potential for eHealth and Insights from a Global Perspective



Chao Sun
孙超

Stellingen behorende bij het proefschrift getiteld

Promoting Health Education and Behavior Change for Chronic Lung Disease：Potential for eHealth and Insights from a Global Perspective

1. Health education that ignores the socioeconomic, geographic, cultural, and health system context is destined to fail. (this thesis)
2. eHealth literacy is not merely an individual skill but is shaped by broader structural conditions such as digital coverage, engagement and trust in eHealth. (this thesis)
3. Digital health education has potential in improving disease awareness and health outcomes, with good feasibility, acceptability and user satisfaction. (this thesis)
4. Despite the limitations, vignette-based methods are indispensable for identifying behaviors that are unethical or impossible to observe directly. (this thesis)
5. Research findings from high-income countries cannot be generalized to low- and middle-income countries. (research field)
6. eHealth risks widening health disparity without addressing inequalities in digital access and skills. (research field)
7. Equitable eHealth can only be achieved by involving multiple stakeholders in its design, implementation, and evaluation. (research field)
8. eHealth interventions should be tailored to local needs and contexts. (this thesis/research field)
9. Applying qualitative rigor criteria to qualitative research undermines its scientific credibility rather than strengthening it. (this thesis/research field)
10. Good research should benefit society, rather than merely achieving publications in top journals.
11. A successful PhD trajectory requires not only personal perseverance and motivation, but also collaborative teamwork, a hobby beyond academia, and a healthy mindset and lifestyle.
12. Multidisciplinary collaborations enable us to stand higher, see further and think more deeply.

Promoting Health Education and Behavior Change for Chronic Lung Disease：Potential for eHealth and Insights from a Global Perspective

Chao Sun

孙超

Promoting Health Education and Behavior Change for Chronic Lung Disease：Potential for eHealth and Insights from a Global Perspective

Leiden University Medical Center

Department of Public Health and Primary Care

© Chao Sun, 2026

Cover design and layout: Chao Sun

Print: Proefschriftmaken | www.proefschriftmaken.nl

ISBN: 978-94-6534-625-0

All rights reserved. No part of this thesis may be reproduced, stored, or transmitted in any form or by any means without prior permission of the author.

Promoting Health Education and Behavior Change for Chronic Lung Disease：Potential for eHealth and Insights from a Global Perspective

Proefschrift

ter verkrijging van

de graad van doctor aan de Universiteit Leiden,

op gezag van rector magnificus prof.dr. S. de Rijcke,

volgens besluit van het college voor promoties

te verdedigen op woensdag 28 oktober 2026

klokke 10.00 uur

door

Chao Sun

geboren te Yiyang, China

in 1998

Promotors:

Prof. dr. N.H. Chavannes

Dr. E. Meijer

Co-promotor:

Dr. M.J. Kasteleyn

Leden promotiecommisse:

Prof. dr. H.M.M. Vos

Prof. dr. O.C.P. van Schayck, Maastricht University

Dr. T.N. Bonten

Dr. H. Shen, Guangzhou Medical University, China

Contents

Chapter 1	General introduction	3
Chapter 2	Beliefs, perceptions and behaviors regarding chronic lung disease in Kyrgyzstan: a mixed-method FRESHAIR study	13
Chapter 3	Beliefs, perceptions and helping behaviors regarding chronic lung disease among healthcare professionals in Kyrgyzstan: a mixed-method FRESHAIR study	43
Chapter 4	eHealth literacy in the general population: a cross-sectional study in China	67
Chapter 5	Digital health education for chronic lung disease: scoping review	107
Chapter 6	Effects of illness perceptions and eHealth literacy on effectiveness of a digital inhaler program for asthma in the Netherlands: post-hoc moderation analyses of a cluster randomized controlled trial	137
Chapter 7	General discussion	157
Portfolio	The PhD trajectory – an overview	172
	CRediT statement	175
	Bibliography	176
	Academic training and activities	178
Appendixes	Summary	182
	Nederlandse samenvatting	185
	总结	188
	Dankwoord	190
	Curriculum Vitae	192

Chapter 1

General introduction

1.1 Global burden of chronic lung disease

Chronic lung disease (CLD), primarily Chronic Obstructive Pulmonary Disease (COPD) and asthma, poses a large health burden around the world. CLD typically develops slowly and worsens over time, affecting the lungs and other parts of the human body, with symptoms such as shortness of breath, wheezing, chronic cough and chest tightness [1, 2]. With a polygenetic basis that contributes high morbidity and mortality [3], CLD risk factors include exposure to tobacco smoke, air pollution, occupational exposure to chemicals and dust, and frequent lower respiratory infections during childhood [4], which are modifiable in contrast to genetic predisposition. According to the latest Global Burden of Disease study in 2023, CLD accounted for 569.2 million cases and 4.2 million deaths worldwide [5]. In the WHO European region, including most of Europe, the Middle East and Central Asia, despite the progress in reducing CLD mortality, substantial disparity exists, with high prevalence in the west but high hospitalization and mortality rates in the east [6]. In the Western Pacific region countries such as China, Japan and Australia, COPD and asthma were the main contributors to CLD burden, with an increasing trend in the group aged 20–54 years [7]. These patterns indicate that the burden of CLD is unevenly distributed across regions and populations, imposing substantial health costs. In particular, low- and middle- income countries (LMICs) face greater challenges and a heavier burden, while receiving less research funding than high- income countries (HICs) [6-8].

1.2 Health education and behavior change for CLD

Given the substantial global health burden of CLD, promoting health education and behavior change is essential for improving CLD prevention and management. Health education aims to empower individuals to initiate lifestyle-related behavior changes that promote positive health status outcomes through a planned, continuous and dynamic teaching-learning process [9], including increasing individuals' understanding of CLD and adopting healthy behaviors such as seeking timely healthcare and adhering to prescribed medications. Healthcare professionals (HCPs) play an important role in providing health education, delivering quality care, performing sufficient and professional helping behaviors across CLD prevention, diagnosis, treatment and management. In addition, the accessibility and affordability of healthcare services shape the adoption of health behaviors and related outcomes [10, 11]. Health education extends beyond the mere dissemination of health-related information to foster the motivation, skills and confidence necessary to take action to improve health. In addition,

it involves communication of information about social, economic and environmental conditions impacting health, individual risk behaviors, as well as appropriate use of the health care system [12]. Effective health education strategies incorporate several core components: participant involvement, planning, needs and resources assessment, a comprehensive and integrated program, long-term change in health behaviors, altering community norms, research and evaluations [12]. However, across diverse global contexts, several challenges persist in translating health education into effective and sustained behavior change. These challenges include, but are not limited to, limited awareness and misperceptions of CLD, prevalent and difficult-to-change risk behaviors and inappropriate CLD-related behaviors among individuals and HCPs.

1.2.1 Limited awareness and misperceptions about CLD

Limited awareness and misperceptions about CLD have been reported and may hinder early detection. In some populations, typical CLD-like symptoms were usually normalized and attributed to communicable diseases, acute infections or environmental exposures, rather than chronic diseases [13, 14]. For example, researchers from the FRESHAIR [15] project, an implementation research project exploring the prevention, diagnosis and treatment of CLD in low-resource settings, found that community members in Vietnam, Kyrgyzstan and Uganda strongly considered long-lasting respiratory conditions as infections, predominantly tuberculosis [13]. Witchcraft and a hot–cold imbalance were misperceived as potential causes [13]. In Kyrgyzstan, COPD was an unfamiliar term to local communities, where CLD-like conditions were often treated as colds or exposure to low temperatures at high altitude [14]. These illness perceptions towards CLD and its causes vary across different cultural and geographical contexts. Moreover, COPD receives limited attention in the public media, leaving the experiences of those living with this common and serious condition largely unheard [16]. However, in-depth studies are scarce exploring these context-specific beliefs and perceptions, which further shape their awareness and CLD-related behaviors.

1.2.2 Promoting behavior change regarding CLD is challenging

Promoting behavior change regarding CLD is challenging not only at the individual level but also among HCPs responsible for CLD diagnosis and management. For individuals, risk behaviors associated with CLD are prevalent and difficult to change, such as smoking tobacco and burning solid fuels for cooking and heating. Despite a substantial decline, the global smoking prevalence remains high, with 32.6% and 6.5% in male and female adults, respectively, in 2020 [17]. Notably, around 80% of the tobacco users worldwide live in LMICs [18], and over half of all men continued to

smoke in large populations in Asia, as well as the Pacific Islands [17]. For smoking cessation, individuals usually struggle due to nicotine addiction, lack of motivation for quitting, limited support from family and community, insufficient professional assistance and absence of strategies for managing triggers and changing habits [19]. Regarding solid fuels use, currently around 2.1 billion people worldwide rely on biomass (e.g., wood, animal dung, crop waste) and coal for cooking and heating [20], exposing them to household air pollution and increasing risk of CLD. Despite awareness of the adverse health impacts from household air pollution, changing energy-use behaviors is challenging mainly due to the limited affordability and accessibility of clean fuels [21].

For HCPs, standardizing their professional helping behaviors in clinical practice to ensure effective CLD care is also challenging. For example, although spirometry is the gold standard for diagnosing CLD, its use remains low due to limited resources or a lack of trained technicians in countries such as Germany and Australia, leading to the underdiagnosis of CLD [22-24]. Another example concerns poor adherence to clinical guidelines: overuse of inhaled corticosteroids was reported to be common in the Netherlands and nearly 50% of COPD patients were not managed in accordance with the recommendations of the Global Initiative for Chronic Obstructive Lung Disease strategy in 2023 [25]. In LMICs, these challenges may be further exacerbated by constrained healthcare resources and insufficient training opportunities for HCPs, resulting in delayed diagnosis and suboptimal CLD management. However, while risk behaviors of CLD have been widely known, other CLD-related behavioral challenges such as help-seeking, HCPs' helping behaviors, and the underlying reasons for these behavior patterns are largely unknown, limiting the development of targeted and effective interventions.

1.3 Benefits of eHealth

eHealth, or digital health, referring to the use of information and communication technologies (ICT) in support of health or health-related field [26], has demonstrated substantial potential in CLD management. The primary benefit of eHealth lies in its ability to overcome time or geographical barriers through mediums such as computers, mobile applications, and wearables [27]. Compared with traditional health education approaches, including face-to-face education, posters, and pamphlets, eHealth has the potential to increase the efficiency and accessibility of healthcare delivery, especially in remote and rural areas. Other benefits include possibilities to tailor treatments or interventions, and design interfaces based on individual characteristics, capabilities and

preferences [28]. For behavior change, eHealth has shown efficacy in enhancing exercise ability in CLD patients by delivering healthcare service remotely such as monitoring, virtual consultations and patient-provider communications [29]. Another example is digital inhalers, which combine inhalers, sensors and mobile applications, that have been found to improve medication adherence in the short term among asthma patients [30]. Despite the benefits of eHealth, individuals differ in their eHealth literacy (eHL) levels, namely the ability to seek, find and understand and appraise health information through ICT [31]. As a result, it may lead to unequal benefits of eHealth interventions. In addition, the Global Strategy on Digital Health 2020-2027 [32] calls on countries and stakeholders to align digital health initiatives with national health priorities and available resources. However, there remains a limited understanding of how eHealth supports health education and behavior change for CLD across populations with varying levels of eHL and within diverse contexts.

1.4 Aims and settings

Currently, there is limited evidence providing in-depth insights into context-specific beliefs, perceptions and behaviors related to CLD, as well as how eHealth supports health education and behavior change across diverse populations and contexts. Therefore, the overall aim of this thesis is to enhance understanding of health education needs and behavior challenges regarding CLD, and to examine the potential of eHealth in supporting CLD health education and behavior change in different contexts. To provide a global perspective, this thesis draws on research conducted in three countries with distinct social, economic, geographic and healthcare contexts: Kyrgyzstan, China and the Netherlands, each of which face a large burden of CLD.

Kyrgyzstan is a mountainous and landlocked LMIC in Central Asia, with high altitudes, distinct lifestyles and climates in the highlands and lowlands. The population in this country is at risk due to exposure to air pollution and smoking [33], with a considerable clinical and economic burden of CLD [34]. The healthcare system of Kyrgyzstan faces challenges including financial constraints and shortages of trained HCPs, particularly in rural highland regions [33, 35]. China, as a rapidly developing LMIC in East Asia, is vast and characterized by large population diversity, well-developed infrastructure and advanced technologies, with evident regional disparities such as east-west and urban-rural gaps. Both COPD and asthma in China account for a large number of prevalent cases and have shown an increasing trend due to rapid urbanization over the past three decades [36, 37]. After 2020, the digital transformation in China's healthcare system entered an internet-based stage, supported by policies that promote a digital health

system [38]. The Netherlands represents a HIC in West Europe, with a well-established healthcare system, widespread digital coverage and a high level of digital competency, with 82.7% of the population possessing basic digital skills [39]. Approximately 2 million people in the country live with COPD or asthma [40].

Using examples from Kyrgyzstan, China, and the Netherlands, this thesis pursues the following specific aims to:

1) explore beliefs, perceptions and behaviors related to CLD;

2) assess eHL and its determinants;

3) evaluate the potential of eHealth for CLD health education and behavior change.

1.5 Thesis outline

In this thesis, **Chapter 2** and **Chapter 3** explore the beliefs, perceptions and CLD-related behaviors among community members and HCPs, respectively, in Kyrgyzstan with mixed-method designs to understand the local health education needs and behavior challenges. **Chapter 4** investigates eHL and its predictors in the Chinese general population, providing additional evidence to inform health education. To evaluate the potential of eHealth, **Chapter 5** provided an overview of existing literature on digital health education for CLD, with a focus on delivery mediums, educational content, intervention mechanisms, and reported outcomes in CLD patients. Considering individual differences, **Chapter 6** explores the moderation effects of illness perceptions and eHL on effectiveness of a digital inhaler program among asthma patients in the Netherlands, and the associations of illness perceptions and eHL with demographics through a post-hoc analysis of a cluster randomized controlled trial. **Chapter 7** summarizes the main findings, interpretations, recommendations and implications, methodological considerations, strengths and limitations, and conclusions of the thesis.

Abbreviations

CLD: chronic lung disease.
eHL: eHealth literacy.
HCP: healthcare professional.
HIC: high-income country.
ICT: information and communication technologies.
LMIC: low- and middle-income country.

References

1. Chronic lung disease. https://www.cancer.gov/publications/dictionaries/cancer-terms/def/chronic-lung-disease. Accessed 25 June 2024.
2. Warning Signs of Lung Disease. https://www.lung.org/lung-health-diseases/warning-signs-of-lung-disease. Accessed 02 January 2026.
3. Sayers I, John C, Chen J, Hall IP. Genetics of chronic respiratory disease. Nat Rev Genet. 2024;25(8):534-47.
4. Chronic respiratory diseases. https://www.who.int/health-topics/chronic-respiratory-diseases. Accessed 06 May 2023.
5. Oh J, Kim S, Yim Y, Kim MS, Disease GBDGCR, Covid C, et al. Global, regional, and national burden of chronic respiratory diseases and impact of the COVID-19 pandemic, 1990-2023: a Global Burden of Disease study. Nat Med. 2026.
6. Chronic respiratory diseases and health equity by 2050. https://www.who.int/europe/publications/i/item/WHO-EURO-2025-12340-52112-79990. Accessed 12 January 2026.
7. Zha C, Zhu X, Liu Y, Yan T, Liu J, Liu J, et al. The burden of chronic respiratory disease in Western Pacific Region from 1990 to 2021: a systematic analysis for the global burden of disease study 2021. BMC Public Health. 2025;26(1):62.
8. Gould GS, Hurst JR, Trofor A, Alison JA, Fox G, Kulkarni MM, et al. Recognising the importance of chronic lung disease: a consensus statement from the Global Alliance for Chronic Diseases (Lung Diseases group). Respir Res. 2023;24(1):15.
9. Pueyo-Garrigues M, Whitehead D, Pardavila-Belio MI, Canga-Armayor A, Pueyo-Garrigues S, Canga-Armayor N. Health education: A Rogerian concept analysis. Int J Nurs Stud. 2019;94:131-8.
10. Kelly S, Martin S, Kuhn I, Cowan A, Brayne C, Lafortune L. Barriers and Facilitators to the Uptake and Maintenance of Healthy Behaviours by People at Mid-Life: A Rapid Systematic Review. PLoS One. 2016;11(1):e0145074.
11. Waldorf BS, Che SE. Spatial Models of Health Outcomes and Health Behaviors: The Role of Health Care Accessibility and Availability. In: Páez A, Gallo J, Buliung RN, Dall'erba S, editors. Progress in Spatial Analysis: Methods and Applications. Berlin, Heidelberg: Springer Berlin Heidelberg; 2010. p. 339-62.
12. Health education: theoretical concepts, effective strategies and core competencies: a foundation document to guide capacity development of health educators. https://iris.who.int/handle/10665/119953. Accessed 12 January 2026.
13. Brakema EA, van der Kleij R, Poot CC, An PL, Anastasaki M, Crone MR, et al. Mapping low-resource contexts to prepare for lung health interventions in four countries (FRESH AIR): a mixed-method study. Lancet Glob Health. 2022;10(1):e63-e76.
14. Sun C, Kasteleyn MJ, Brakema EA, Poot CC, van der Kleij RM, Chavannes NH, et al. Beliefs, Perceptions, and Behaviors Regarding Chronic Lung Disease in Kyrgyzstan: A Mixed-method FRESHAIR Study. 2025:2025.11. 19.25338955.
15. Cragg L, Williams S, Chavannes NH. FRESH AIR: an implementation research project funded through Horizon 2020 exploring the prevention, diagnosis and treatment of chronic respiratory diseases in low-resource settings. NPJ primary care respiratory medicine.

2016;26:16035.
16. Shining a spotlight on COPD - raising awareness through media workshops. https://www.who.int/news/item/18-11-2025-shining-a-spotlight-on-copd---raising-awareness-through-media-workshops. Accessed 12 January 2026.
17. Dai X, Gakidou E, Lopez AD. Evolution of the global smoking epidemic over the past half century: strengthening the evidence base for policy action. Tob Control. 2022;31(2):129-37.
18. Tobacco. https://www.who.int/news-room/fact-sheets/detail/tobacco. Accessed 12 January 2026.
19. Pereira MO, Assis BCS, Gomes NMR, Alves AR, Reinaldo A, Beinner MA. Motivation and difficulties to reduce or quit smoking. Rev Bras Enferm. 2020;73(1):e20180188.
20. Household air pollution. https://www.who.int/news-room/fact-sheets/detail/household-air-pollution-and-health. Accessed 12 January 2026.
21. Das D, Ahmad S, Kirshner J. Opportunities and Challenges Associated with the Uptake of Residential Clean Fuel Usage. Curr Environ Health Rep. 2024;11(2):204-9.
22. Hartel A, Peters M, Kostev K. Prevalence of Spirometry Testing among Patients with Asthma and COPD in German General Practices. Healthcare (Basel, Switzerland). 2022;10(12).
23. Lim R, Smith T, Usherwood T. Barriers to spirometry in Australian general practice: A systematic review. Aust J Gen Pract. 2023;52(9):585-93.
24. Almagro P, Soriano JB. Underdiagnosis in COPD: a battle worth fighting. The Lancet Respiratory medicine. 2017;5(5):367-8.
25. Cuperus LJA, De Jong G, Bischoff E, Van Boven JFM, Van der Palen J, Aerts J, et al. Adherence to Inhaled Medication Guidelines in Patients with COPD: Evaluating the GOLD 2023 Strategy in a Real-World Secondary Care Setting. Int J Chron Obstruct Pulmon Dis. 2025;20:3877-91.
26. eHealth. https://www.emro.who.int/health-topics/ehealth/. Accessed 18 January 2026.
27. Kuwabara A, Su S, Krauss J. Utilizing Digital Health Technologies for Patient Education in Lifestyle Medicine. Am J Lifestyle Med. 2020;14(2):137-42.
28. Sebri V, Savioni L. An Introduction to Personalized eHealth. In: Pravettoni G, Triberti S, editors. P5 eHealth: An Agenda for the Health Technologies of the Future. Cham: Springer International Publishing; 2020. p. 53-70.
29. Yoon HY, Song JW. Telemedicine in chronic lung disease management: progress and prospects. The Korean journal of internal medicine. 2026;41(1):31-46.
30. van de Hei SJ, van den Berg LN, Poot CC, Gerritsma YH, Meijer E, Flokstra-de Blok BMJ, et al. Long-Term Effectiveness of a Digital Inhaler on Medication Adherence and Clinical Outcomes in Adult Asthma Patients in Primary Care: The Cluster Randomized Controlled ACCEPTANCE Trial. The journal of allergy and clinical immunology In practice. 2025;13(7):1693-704.
31. Norman CD, Skinner HA. eHealth Literacy: Essential Skills for Consumer Health in a Networked World. J Med Internet Res. 2006;8(2):e9.
32. Global strategy on digital health 2020-2027: World Health Organization; 2025.
33. Rechel B, Moldoisaeva S, Shriwise A. Health Systems in Action (HSiA) Insights–Kyrgyzstan. 2025.
34. Tabyshova A, Estebesova B, Beishenbekova A, Sooronbaev T, Brakema EA, Chavannes

NH, et al. Clinical Characteristics, Treatment Patterns and Economic Burden of COPD in Kyrgyzstan: A FRESH AIR Study. Int J Chron Obstruct Pulmon Dis. 2021;16:2833-43.
35. Improving health care. https://www.unicef.org/kyrgyzstan/improving-health-care. Accessed 15 December 2024.
36. Dong F, Su R, Ren Y, Yang T. Burden of chronic obstructive pulmonary disease and risk factors in China from 1990 to 2021: Analysis of global burden of disease 2021. Chin Med J Pulm Crit Care Med. 2025;3(2):132-40.
37. The Global Asthma Report 2022. https://globalasthmareport.org/regions/china.php. Accessed 23 March 2026.
38. Wang M, Lu X, Du Y, Liu Z, Li X, Zhao X, et al. Digital health governance in China by a whole-of-society approach. NPJ Digit Med. 2025;8(1):496.
39. Netherlands 2024 Digital Decade Country Report. https://digital-strategy.ec.europa.eu/en/factpages/netherlands-2024-digital-decade-country-report. Accessed 18 January 2026.
40. Action for lung health in the Netherlands. https://international-respiratory-coalition.org/countries/netherlands/. Accessed 23 March 2026.

Chapter 2

Beliefs, Perceptions, and Behaviors Regarding Chronic Lung Disease in Kyrgyzstan: A Mixed-method FRESHAIR Study

Chao Sun, Marise J. Kasteleyn, Evelyn A. Brakema, Charlotte C. Poot, Rianne M.J.J van der Kleij, Niels H. Chavannes, Maamed Mademilov, Talant Sooronbaev, Eline Meijer

npj Primary Care Respiratory Medicine (under review, preprinted)

doi:10.1101/2025.11.19.25338955

Chapter 2

Abstract

Introduction: Chronic lung disease (CLD) represents a substantial health burden in low- and middle-income countries (LMICs). However, in-depth CLD studies in Kyrgyzstan, where CLD is highly prevalent, remain scarce.

Objectives: To explore in Kyrgyzstan (1) beliefs, perceptions and behaviors regarding CLD among community members (CMs), (2) relations between illness perceptions, demographics, behaviors and setting (highlands vs. lowlands), and (3) illness perception profiles across subgroups.

Methods: Qualitative data were gathered through semi-structured interviews and focus groups and analyzed using a Framework Method. Quantitative data were collected via questionnaires including the brief Illness Perception Questionnaire (B-IPQ), measures of smoking, indoor heating and cooking, and help-seeking behaviors. Univariable and multivariable linear regression analysis and latent class analysis (LCA) were conducted. Triangulation integrated qualitative and quantitative findings.

Results: We included 8 interviews, 13 focus groups, and 420 questionnaires. CMs held misperception about CLD and its causes, continued smoking despite perceived harms and prevention efforts, used risk fuels with limited ventilation, and delayed help-seeking. CMs obtained a mean B-IPQ score of 23.4 (SD 2.1), with longer duration of education, lowland setting, and being unemployed significantly associated with higher B-IPQ scores ($p<0.05$). LCA identified 2 subgroups: highlanders were more likely to be in class 1 whereas lowlanders in class 2 ($\chi 2=5.95$, $p=0.01$).

Conclusion: Misbeliefs and misperceptions about CLD, smoking, household risk behaviors, and delayed help-seeking were prevalent in Kyrgyz CMs. Longer education, being unemployed and living in the lowlands were associated with more negative illness perceptions. Two distinct subgroups based on B-IPQ profiles were identified: one with more negative perceptions in the consequence, symptoms, concern and emotion, while the other perceived more negatively in the timeline, treatment and understanding. Targeted education in CLD, smoking cessation support should be provided for the public to improve the awareness, prevention, and care of CLD in Kyrgyzstan.

Introduction

Chronic lung disease (CLD) encompasses a group of long-term conditions affecting the airways and lungs, including chronic obstructive pulmonary disease (COPD), asthma, pneumonitis, and other lung conditions [1]. Main risk factors for CLD include direct factors, such as smoking, indoor and outdoor air pollution and occupational exposure, as well as indirect factors like low socioeconomic position (SEP) [2-4]. Alarmingly, over 75% of global COPD cases [5] and 90% of asthma cases [6] occur in low- and middle-income countries (LMICs). These regions often face under-resourced healthcare systems, lack of comprehensive policy and practical local guidelines for CLD diagnosis and management, contributing to low rates of diagnosis and treatment [7, 8]. Despite this high burden, the minority of global CLD research funding is concentrated in LMICs, often focusing predominantly on smoking, and less on other critical risk factors like household air pollution (HAP) due to cooking and heating behaviors [9].

To design effective interventions targeting these risk factors, it is essential to understand the beliefs, perceptions and behaviors regarding CLD in LMICs. Researchers from the FRESHAIR project [10], an implementation research project that aimed to improve lung health in low-resource settings, emphasized the necessity of understanding local needs, engaging key stakeholders, and ensuring adequate access to knowledge [11]. In many LMICs, disease beliefs, perceptions, and behaviors are shaped by deeply rooted traditions and cultural norms. For example, smoking may symbolize masculinity, coal-burning rituals is practiced in post-partum care (e.g. Vietnam), and CLD like symptoms might be attributed to witchcrafts or spirits (e.g. Kyrgyzstan) [12]. These indicate limited awareness and increased vulnerability to CLD risk factors among local populations. In Bangladesh, CLD patients rarely know the disease and causes [13]. Similarly, in rural Uganda, a lack of awareness and health seeking behavior, fear of diagnosis, hindered the adoption of the COPD screening program [14]. These examples underscore the importance of understanding the local beliefs, perceptions and behaviors for developing contextual and successful interventions.

Kyrgyzstan is a relevant and under-researched example within this context. It is a landlocked, mountainous country in central Asia, with 94% of its land above 1000 meters and an average elevation of 2750 meters above sea level [15]. CLD is recognized as one of the main non-communicable diseases in the country [16], with COPD particularly imposing a substantial clinical and economic burden [17]. Contributing factors include high altitude and extreme climate, widespread smoking, and limited

access to clean fuels for cooking and heating [16, 18, 19]. Highland and lowland populations however differ substantially in risk exposure and lifestyle. Highland communities face harsher weather and, consequently rely more on biomass fuel for cooking and heating, while mountainous terrain also hinders local infrastructure development [20]. In contrast, lowland areas have milder climates and better access to healthcare, education and infrastructure. Nonetheless, both settings face challenges such as limited healthcare access, shortages of medical supplies and trained staff, and underfunding [21], hindering disease diagnosis, treatment, and care. Despite the high prevalence of CLD in Kyrgyzstan [17], few studies explored in depth beliefs, perceptions, and behaviors regarding CLD among local populations.

To achieve the global goal of a 25% reduction in premature mortality from main non-communicable diseases (NCDs), including CLD by 2025, one of the World Health Organization package of essential NCD interventions (PEN) was initiated in Kyrgyzstan in 2015 [22]. PEN is a conceptual framework for strengthening equity and efficiency in primary health care in low-resource settings. However, the implementation of PEN in Kyrgyzstan appears to be ineffective in prespecified performance and effectiveness indicators [22].

The current study aims to explore the beliefs, perceptions, and behaviors of local community members (CMs) regarding CLD in Kyrgyzstan. Our insights will ultimately provide a better understanding of the local barriers in CLD prevention and care, contributing to the global and sustainable development goals for addressing NCDs. Using a mixed-method study design, we collected data through semi-structured interviews, focus groups, and questionnaires to address the following research questions within the context of Kyrgyzstan:

1. What are the beliefs and perceptions regarding CLD symptoms among CMs in the highlands and lowlands?
2. What are the risk behaviors and help-seeking behaviors of CMs related to CLD in the highlands and lowlands?
3. How do demographics, setting (highlands vs lowlands) and behaviors regarding CLD relate to illness perceptions?
4. What subgroup profiles can be identified based on illness perceptions among CMs?

Methods

Study design

This is an exploratory mixed-method study as part of the FRESHAIR project [10],

focusing on the prevention, diagnosis, and treatment of CLD in low-resource settings (see [10] for more details). Data were collected in Kyrgyzstan highlands (Naryn) and lowlands (Chui) in May 2016. Qualitative data collection included individual in-depth interviews and focus groups. Quantitative data was collected with questionnaires. All Data collection tools (topic lists and questionnaires) were guided by a theoretical framework that combined three health behavioral models: the Theory of Explanatory Models of Illness [23], the Theory of Planned Behavior [24], and the Health Belief Model [25]. Details were published previously [12].

Participants and sampling

We included the following participants: 1) CMs aged at least 18 years; 2) Key informants (KIs) with either in-depth knowledge or an overall overview of community beliefs, perceptions and behaviors: e.g., religion or community leaders, traditional healers, pharmacists and teachers. People were excluded if they were not able to participate in the study due to severe physical or mental illness or could not provide formal informed consent.

For the qualitative data collection, purposive sampling was applied to reach a diverse population with sufficient variation in sex, age, educational level and profession. Potential participants who met the inclusion criteria were identified based on snowball sampling and opportunity. Sample size was determined based on data saturation when no new themes or information were emerging from collected data. For the quantitative part, a three-stage sampling approach was applied to randomly select CMs, as published previously [26]. We expected to reach 200 CMs per setting.

Procedure

Rapid Appraisal approach [27] was applied to collect qualitative and quantitative data in an effective and iterative way. Researchers immersed themselves into the field and built trust with CMs in advance.

Qualitative data

Semi-structured interviews and focus groups were performed by an experienced qualitative researcher and a trained local healthcare researcher for English interpreting. Interviews and focus groups took place in a private place to encourage participants to speak more freely, each lasting approximately 1 hour. Each focus group consisted of 3-6 participants with the same level of hierarchy to avoid hierarchical influence that could inhibit open discussions. Audio was recorded during interviews and focus group. Fieldnotes were recorded when necessary. At the end of each qualitative data collection,

a short summary and reflection were discussed with team members.

Quantitative data

Hardcopy questionnaires were distributed to CMs by researchers after a pilot test. Additional explanation was provided by researchers in case of any difficulty in understanding questionnaires for participants. Daily meetings after data collection were held for experience exchanges and context-specific adjustments were made according to CMs' feedback (e.g., rainy/dry season instead of summer/winter) [26].

Measures

All measures were described based on the FRESHAIR protocol, details published previously [12].

Interviews and focus groups

Interviews and focus groups were guided by a topic list based on the theoretical framework. After an introduction and obtaining informed consent, demographic information (gender, age, education, profession) was collected. A vignette was used, presenting a case scenario of a relatively young woman, Anna, with CLD signs to avoid potential stigmatization. Questions and probes were used to explore participants' beliefs and perceptions about CLD, smoking, cooking and heating behaviors, and help-seeking behaviors for CLD. The topic list was tailored to CMs and KIs, and to interviews and focus groups.

Questionnaires

Demographics

Demographics asked included gender, age in years, education (in years, "In total, how many years have you spent at school and in full-time study?"), and occupation (1= housewife/man, 2 = unemployed (able to work), 3 = unemployed (unable to work), 4 = retired, 5 = traditional farming and agricultural service, 6 = education or social services, 7 = healthcare service, 8 = manufacturing, 9 = transportation, 10 = construction, 11 = others). 'other' occupations category, was recategorized into unemployed (housewife/man, retired, unemployed) and employed (all other categories).

Beliefs and perceptions about CLD

Beliefs and perceptions about CLD were measured with the revised Brief Illness Perception Questionnaire (B-IPQ) [28]. The B-IPQ is a validated questionnaire consisting of nine items (consequence, timeline, personal control, treatment, identity,

concern, understanding, emotion, and cause) which can be applied to various diseases, and has good reliability and validity [28]. The B-IPQ employs a 0-to-10 response scale. During pilot testing the original 10 scale was not understood as intended. To ensure internal validity we adapted the response scale into a 4-point scale (1 = not at all, 2 = slightly, 3 = fairly, 4 = very well) except item 2 (1=for days, 2=for weeks, 3=for months, 4=for years). The item 9 was originally an open question about causes of CLD. As we expected local CMs were not familiar with CLD causes, we replaced item 9 with 24 potential options and asked them to score whether they think these are causes of CLD with a 5-point Likert scale (from 1 = strongly disagree to 5 = strongly agree), as was done in FRESHAIR project before [12]. The total B-IPQ score was calculated by summing all 8 items, with item 3, 4, 7 reverse-scored to ensure consistency in interpreting higher scores as reflecting more negative or severe illness perceptions, ranging from 8 to 32.

Behaviors regarding CLD

We assessed CMs' intended help-seeking behavior, smoking, and household risk behaviors such as cooking, heating, and ventilation. Intended help-seeking behavior was assessed by asking "Suppose you had the same condition as Anna, who would you seek for help (partner, friend, traditional healer, general practitioner or primary care doctors, would not seek help etc.)".

Smoking behavior was assessed by asking "Do you currently smoke any tobacco products, such as cigarettes, cigars or pipes (yes vs no)", "Do you currently smoke tobacco products daily (yes vs no)" and "Did you smoke daily in the past (yes vs no)". For later analysis, smoking was recategorized into no smoking, current smoking and previous smoking.

To quantify the household risk behavior, the household risk behavior score was calculated. Cooking or heating with open or surrounded fire, using risk fuels (e.g., dung, grass, wood, chalk, kerosene), and lack of ventilation were scored 1 for each factor. Considering potential season differences, summer and winter were scored separately. The total score of household risk behavior was then calculated as the sum of these factors, ranging from 0 to 12. Higher scores indicate more frequent household risk behaviors.

Reflexivity

The research team comprised both local and international researchers from Kyrgyzstan, The Netherlands and China, with diverse backgrounds in respiratory medicine, general practice, psychology, public health, epidemiology, and implementation science. This

diversity enriched our interpretations and helped to mitigate bias through team discussions, peer debriefing, and consultation with local stakeholders. Additionally, we are aware of the risks of smoking and HAP, which shaped our interpretations to the data.

Data analyses

Triangulation was conducted during data analyses. After themes were identified from qualitative data, quantitative findings were compared and complemented to provide more detailed information.

Qualitative data

For RQ1 and RQ2, a Framework Method [29] was used to identify themes emerged from qualitative data. Data were transcribed verbatim and translated into English by the local interpreters who are proficient in Kyrgyz, Russian and English. Transcripts were imported into ATLAS.ti 19.0 for coding and analysis. Each transcript was assigned an study ID. An initial set of open codes were developed inductively and deductively based on 3-5 transcripts with the theoretical framework by two independent researchers. Then these codes were applied to the rest of transcripts. After coding was completed, codes were grouped into categories and then organized into themes and subthemes. All codes and quotes were discussed and reviewed by team members (CS, MK, EM), with discrepancies resolved though consensus. Feedback from Kyrgyz researchers (MM, TS) was incorporated to ensure consistency and validity.

Quantitative data

For RQ1 and RQ2, descriptive analyses were conducted by reporting frequencies and percentages for categorical variables, means (M) and standard deviations (SD) for normally distributed continuous variables, and medians and interquartile ranges (IQR) for non-normally distributed variables.

For RQ3, univariable and multivariable linear regression analyses were conducted in SPSS 22.0. Demographics, setting, and behavioral indicators were entered into regression analyses separately as determinants, and total B-IPQ scores as the dependent outcome. All variables with significant associations with total B-IPQ scores ($p<0.05$) were then entered into a multivariable regression model in the same step. For RQ4, latent class analysis (LCA) was applied to B-IPQ scores to identify potential subgroups. The poLCA package [30] was used in R 4.4.2. A series of LCA models were fit by starting with a one-class model and iteratively adding an additional class. The best model was selected based on the likelihood ratio test (LL), the Bayesian Information Criterion (BIC), Akaike Information Criterion (AIC), relative entropy and parsimony

[31]. Lower LL, BIC, AIC indicate better models, and the BIC has been considered as the accurate fit measure. Relative entropy >0.8 indicates a good certainty in classification [32]. We performed LCA by fitting models from 1 to 5 classes with a maximum of 1000 iterations and repeated each analysis 100 times. Default settings were used for other options. After LCA, independent sample t-tests, Chi-square tests and Mann-Whitney U tests were conducted to examine whether class membership was associated with demographics, setting, and behavioral indicators. To further characterize the class profiles, t-tests were used to compare each B-IPQ item scores between classes. We ensure that the assumptions of all analyses were met.

Ethical considerations

Prior to data collection, an explanation of the study purpose, procedures, potential risks and benefits, and data privacy and security were provided and informed consent hardcopies were obtained from all participants by team members. To mitigate risks of sensitive information disclosure and potential burden of participation, we ensured participation was voluntary and informed participants that they could withdraw at any time. Data could be accessed by the core research team members only and all data were pseudonymized to maintain confidentiality. Ethical approval was acquired from the Leiden University Medical Centre Medical Ethical Committee (P16.063;04/15/2016) in the Netherlands and the National Centre of Cardiology and Internal Medicine in Bishkek Ethics Committee (5;03/03/2016) in Kyrgyzstan.

Results

Background characteristics

We included 8 individual interviews, 13 focus groups (n=45), and 420 questionnaires (Appendix 1). In the qualitative phase, a total of 53 participants were involved, including 25 (47.2%) males and 28 (52.8%) females, with a diverse age and various occupational backgrounds. Questionnaire participants had a mean age of 47.0 years, including 185 (44.0%) males and 235 (56.0%) females. Most participants were housewives/men (141, 33.6%) or worked in the traditional farming and agriculture sector (110, 26.2%). A total of 40 (9.5%) participants were diagnosed with CLD. More details are shown in Table 1.

Table 1 Background characteristics of questionnaire participants

Variables	Categories	Highland	Lowland	Total
Total, n (%)		210, 50.0	210, 50.0	420, 100.0
Age, mean (SD)	In years	46.0, 13.6	47.9, 13.1	47.0, 13.3
Gender, n (%)	Male	94, 44.8	91, 43.3	185, 44.0
	Female	116, 55.2	119, 56.7	235, 56.0
Education, median (IQR)	In years	11.0, 3.0	11.0, 3.0	11.0, 2.0
Occupation, n (%)	Housewife/man	69, 32.9	72, 34.3	141, 33.6
	Unemployed (able to work)	7, 3.3	14, 6.7	21, 5.0
	Retired	38, 18.1	36, 17.1	74, 17.6
	Traditional farming and agriculture sector	77, 36.7	33, 15.7	110, 26.2
	Education or social service	15, 7.1	20, 9.5	35, 8.3
	Healthcare service	0, 0	7, 3.3	7, 1.7
	Manufacturing, transportation, construction	0, 0	25, 11.9	25, 6.0
	Others[a]	4, 1.9	3, 1.4	7, 1.7
Diagnosed with CLD, n (%)	Yes (vs. no)	31, 14,8	9, 4,3	40, 9.5
Smoking status, n (%)	No smoking	151, 71.9	139, 66.2	290, 69.0
	Currently smokes	28, 13.3[b]	30, 14.3[c]	58, 13.8
	Previously smoked	31, 14.8	41, 19.5	72, 17.1

a: including entrepreneur (n=1), guard (n=4), seller (n=1), student (n=1).

b: male (28, 6.7%), female (0, 0%).

c: male (28, 6.7%), female (2, 0.5%).

Beliefs, perceptions and behaviors regarding CLD

Theme 1: misperceptions about CLD and its causes

Misperceiving CLD symptoms as acute, infectious conditions

Most participants demonstrated limited understanding of CLD, frequently misperceiving the symptoms presented in the vignette as a common cold, flu or tuberculosis. For instance, one participant commented *"Maybe, she has got infected from someone, hasn't she? Maybe flu…If the cough lasts for not more than one month, it might be an ordinary cough" (CM-FG-8-L).* Similarly, a KI noted *"They cough mainly when they have flu. We do also hold the explanatory works on the topics of tuberculosis…If the cough lasts for 2 weeks and this is the sign of the tuberculosis…" (KI-I-11-H)*. Such responses suggest that persistent respiratory symptoms are often perceived as acute or infectious conditions in nature, rather than chronic noncommunicable diseases. This misperception may be reinforced by the "explanatory

works", namely local health education campaigns, which historically placed greater emphasis on infectious diseases than on chronic diseases, as mentioned by this KI.

COPD was not a familiar concept to CMs. When asked what COPD is, one participant responded, *"That's the first time I have heard this (laugh)" (CM-FG-5-L).* Similarly, when asked if Anna could have asthma, there were notable misconceptions about its symptomatology and chronic nature. For example, *"Participant: While having asthma, lungs will be squeezed and there will be shortness of breath, but no cough. Interviewer: Do you all agree that it is not asthma? Participant: Yes, we agree (laugh)" (CM-FG-2-H).* Similarly, a KI stated that *"The fact is that there is a shortness of breath, it might progress to complications and become asthma, but in 2-3 years it is hardly possible for it to become asthma." (KI-I-13-H).* Participants seemed to be more familiar with the term "asthma" than "COPD" but had limited and sometimes inaccurate knowledge about its symptoms and progression. Additionally, participants had difficulty in distinguishing different respiratory illnesses, as illustrated by this KI: *"Interviewer: They can't distinguish the diseases. Participant: Yes, for all respiratory diseases, they call the illness of the lungs…" (KI-I-13-H).* This reflects a lack of disease differentiation and the tendency to lump all respiratory conditions under a general category.

A few participants also mentioned other conditions such as allergy and bronchitis, although these statements were mostly anecdotal, stemming from relatives or neighbors with similar symptoms and mass media. This suggests their reliance on informal or non-evidence-based source of information, which may lack accuracy and limit their understanding of CLD. For example: *"I have an acquaintance. She retired and coughed all the time from dust and when the flowers and grass were blooming. Allergic." (CM-FG-6-L).*

Attribution of CLD to cold and smoking

Regarding possible causes of the illness raised in the vignette, most CMs attributed it to cold, referring either to infection or to cold weather in both highland and lowland settings. For example, one mentioned: *"It should be only because of the cold. When you have fever because of the cold and don't treat yourself, it becomes chronic" (CM-FG-1-L).* The reference to "fever because of the cold" implies they believe it was caused by external microbes, which, if left untreated, could develop into a chronic condition. Another participant, who lived in the highlands, emphasized the role of climatic conditions: *"Here most of the diseases are connected with the highlands, it is cold here. Because of the cold there are health problems with the lungs and other inner organs" (CM-FG-4-H).* This highlights a prevailing belief that cold weather is a direct cause of lung diseases, and even other inner health issues. In addition, some participants

acknowledged behavioral factors, such as smoking, as causes of CLD symptoms. For instance, they replied *"This is from the cigarettes, most probably." (CM-FG-2-H)* and *"Probably, she smokes cigarettes. This can be a reason, or her husband smokes" (CM-FG-8-L).* These statements reflect a partial recognition of smoking— both active and passive smoking— as a cause of CLD, although with uncertainty and limited understanding of the causal relationship.

These qualitative findings were supported by quantitative results. Among 24 potential causes we provided, more than 70% of CMs (strongly) agreed that a germ or virus, kitchen smoke, poor medical care in the past, pollution in the environment, dust, smoking, secondhand smoke, the weather, an allergy, lung infection or tuberculosis in the past, occupational pollution, smoke exposure of mother during pregnancy were causes of CLD, details in Appendix 2.

Theme 2: Continued smoking despite perceived harms and prevention efforts

Smoking is a common behavior shaped by gender norms and role models

Most participants stated that smoking was prevalent in the local community, although they highlighted age and gender differences in smoking prevalence. A village leader in the highlands reflected on this as follows: *"It (smoking prevalence) seems to me 75%...when I look at people standing beside me, there are only a few who do not smoke" (KI-I-13-H)*. A participant in the lowlands estimated that *"around 50% of youngsters smoke, and elderly people do not smoke a lot" (CM-FG-11-L)*. In youngsters, smoking appeared to be related to their paternal practice and peer imitations. Participants noted *"If the father smokes, then the child can also start…In the families where the father does not smoke, it is easier, the child tries not to smoke" (CM-FG-1-L),* and *"there are some in the city, or some of them who study in the city, when they come back, they continue smoking…they have new friends there, who smoke" (CM-FG-4-H).* In the survey, 58 (13.8%) CMs reported to smoke currently and 72 (17.1%) reported previous smoking (Table 1). The use of naswar, a traditional smokeless tobacco, was also prevalent: *"People use naswar more than smoking cigarettes. Naswar gives more pleasure. Men use it more than women, especially the elderly" (CM-FG-5-L).* Male smoking was widely tolerated, whereas female smoking was considered inappropriate. For example, a CM stated that *"the man can be understood… but when women smoke, they are future mothers after all" (CM-FG-5-L).* Another CM explained that *"If girls smoke, it looks a bit strange…but smoking fits them (boys) better than girls" (CM-FG-8-L).* These statements suggested local CMs held different gendered perceptions about smoking, tending to overlook parental roles to men who smoke. One village leader in the highlands added that smoking was linked to idle time during grazing: *"In distant*

villages, smoking became a reason for inhabitants, because most of the time is free and they get distracted by cigarettes, when they herd their sheep or water the fields, they smoke cigarettes…" (KI-13-I-H).

Anti-smoking efforts with limited effectiveness and weak enforcement

Anti-smoking efforts were taking place in schools and communities, including brochures, posters and lectures. As a village leader mentioned, "*We gather 8,9,10,11 classes, play and hold the action where we tell about the harm of the smoking and give the rewarding prizes, there we have brochures…do some posters" (KI-FG-2-H).* Another village leader, also a member of the village health committee, remarked *"we read lectures, show movies about the harm of smoking and naswar, show posters, make seminars with all the visual hangouts" (CM-FG-1-L).* Despite these efforts, tobacco control remained weak, especially regarding youth access: *"We strictly prohibit selling cigarettes to children…We just control and threat in words, but they find the ways" (KI-13-I-H).* Notably, CMs were aware of harms of smoking but highlighted the difficulty of quitting. As one participant mentioned *"of course we know that it is harmful, but if you have started, it is hard to give up smoking" (CM-FG-10-L).*

Theme 3: Cooking and heating with risk fuels and limited ventilation

Risk cooking and heating behaviors were noticed, exposing CMs to potential HAP. CMs reported using a kind of large pot, a "kazan", with open fire, a mix of coal and biomass such as dung and wood for cooking and heating. One participant noted, *"We cook in the kazan outside on the open fire and use biomasses. In winter when it is cold we cook at home…All of us use coal and biomasses" (CM-FG-3-H).* Similarly, another participant shared, *"everybody uses (coals) here" (CM-FG-7-L)*. Although many CMs acknowledged the health risks associated with smoke from coal and biomass, these fuels remained the most commonly used due to their relatively lower cost and ability to retain warmth: *"Coal…keeps the warmth for a long time…it is expensive, but cheaper than electricity" (CM-FG-10-L)*. Ventilation practices were mentioned as partial solutions to reduce smoke exposure, as one participant noted *"when the chimney is clogged, then, the smoke comes out and we clean the chimney" (CM-I-17-H).* Another participant added: *"the smoke comes out, that is why we open windows and doors…We open the doors for 5 minutes (in winter), not so long, while the fire blazes up" (CM-FG-10-L)*. This suggests these ventilation practices were generally limited and dependent on weather conditions. Although electronic oven and gas were seen as cleaner alternatives, their use is constrained by affordability, as noted by CMs in the lowlands: *"We buy gallons of gas and use it only when there is no electricity…It (electricity) is very convenient, but to use it constantly there is big money needed, and*

we cannot afford them with our salaries" (CM-FG-10-L).

The survey demonstrated similar household risk behavior characteristics. As shown in Table 2, many CMs used risk fuels for cooking (summer: 193, 46.0%; winter: 328, 78.1%) and heating (summer: 51, 12.1%; winter: 413, 98.3%) with a noticeable seasonal difference. Access to clean fuels for heating was quite limited (summer: 2, 0.5%; winter: 10, 2.4%). Risk fuel use seemed much more common in the highlands compared to lowlands. Some households had no ventilation when cooking, especially in winter (summer: 3, 0.7%; winter: 83, 19.8%). In the highlands, no ventilation for cooking and heating was common both in summer and winter (Table 2). A sharp increase in reporting no ventilation was noticed in the lowlands, from 0% in summer to 36.2% in winter, suggesting greater sensitivity to seasonal changes here. Additionally, participants had a median household risk behavior score of 5.0 (IQR 1.0) in summer and 7.0 (IQR 0.0) in winter (range: 2-12). This suggests CMs engaged in less frequent household risk behaviors in summer and more frequent in winter. More details are shown in Table 2.

Table 2 Household risk behaviors of community members

	Categories	Summer (n, %)			Winter (n, %)		
		Highland	Lowland	Total	Highland	Lowland	Total
Risk cooking stoves	open/surrounded fire	25, 11.9	7, 3.3	32, 7.6	1, 0.5	0	1, 0.2
Cooking fuels	risk fuels[a]	144, 68.6	49, 23.3	193, 46.0	201, 95.7	127, 60.5	328, 78.1
	clean fuels	121, 57.6	179, 85.2	300, 71.4	18, 8.6	153, 72.9	171, 40.7
Cooking ventilation	no ventilation	3, 1.4	0	3, 0.7	7, 3.3	76, 36.2	83, 19.8
Risk heaters*	open fire/surrounded fire	0	0	0	0	0	0
Heating fuels	risk fuels	51, 24.3	0	51, 12.1	210, 100.0	203, 96.7	413, 98.3
	clean fuels	2, 1.0	0	2, 0.5	0	10, 2.4	10, 2.4
Heating ventilation*	no ventilation	0	6, 2.9	6, 1.4	0	6, 2.9	6, 1.4

*: no difference between summer and winter.

a: solid fuels (e.g., coal, wood, grass, dung) and kerosene.

Theme 4: Delayed help-seeking

Traditional remedies for early respiratory symptoms

In both the highlands and lowlands, traditional remedies were frequently mentioned as a way of relieving early respiratory symptoms, such as cough and sore throat, by applying drinks or food mixed with animal fat, meat, milk, and herbs. For example, one participant mentioned: *"The fat of sheep is applied to the throat. Feet are steamed with the mustard flour. Mustard poultice is applied. And for the sore throat, the fat of badger helps, it is necessary to eat it" (CM-FG-5-L).* This demonstrates the local people tended to treat all respiratory symptoms as ailments and the effectiveness of traditional remedies was widely acknowledged.

Reliance on self-medication and pharmacies over formal care

If symptoms persisted, people were more likely to buy medications at the pharmacy. One participant described: *"they all do self-treatment, only when the case is very hard, they turn to help…I haven't seen them to go to the hospital in a large scale" (CM-FG-7-L)*. This reflects a common pattern of delayed help-seeking, where CMs tended to seek professional medical care only in a severe or advanced stage of disease. When asked what medications they took, one participant responded: *"Antibiotics, antiviral…it is easy (to buy antibiotics), if there are no such medications here, we go to the nearest villages and buy there" (CM-FG-4-H).* This implies antibiotics use was quite common, and they were easily bought in local pharmacies. A key reason for choosing self-medication over formal care was related to accessibility and affordability. For example, some participants noted that medical facilities were far away "*it is 25 km to the nearest drugstore" (CM-FG-11-L)* and hospital visits were costly "*financial problems…there are people, who do not want intentionally" (CM-FG-7-L)*. In addition, a CM in the lowlands reported there was a lack of qualified HCPs that can provide corresponding treatment: *"we do not have the doctor; if we had, we would go to consult him…At our medical post our nurses are not allowed even to use drip bulb" (CM-FG-11-L).* In the highlands, it seemed much harder to consult a doctor or paramedic due to the long distance to medical facilities and transportation problems: *"there is no connection, no gasoline, no car. But in summer it is easier. We ride to the border post on horses and get there by car" (CM-FG-2-H).* These statements suggest that distance to medical facilities and financial burden act as a barrier to access timely and basic healthcare services, especially in remote areas with infrastructure issues.

Healthcare preference shaped by trust, cost and cultural background

When formal care was sought, CMs expressed a greater trust in private hospitals compared to state hospitals, despite higher costs. One participant pointed out the different quality of care between private and state hospitals: *"At state hospital, the doctors… well, I think, they do not treat well…they can make a wrong diagnosis…But*

the private hospitals are better…those who can afford this, they turn to private ones. And those who cannot afford they turn to the state hospital…many will go to the state…" (KI-FG-1-L). This implies CMs with high income could access better healthcare service while those with lower income were left with lower quality of care. Notably, help-seeking behavior also appeared to be linked to ethnic and cultural backgrounds, as a participant with a Kyrgyz ethnical background mentioned: *"In Bishkek I have Russian neighbors, if they have a small problem with their health, they immediately go to see the doctor…We are nomad nation. We're used to herd cattle and didn't know any doctors…" (CM-FG-11-L).* This contrast between Russians and Kyrgyz ethnicities was mentioned by several other participants.

According to the survey, however, most CMs would seek help from general practitioner or primary care doctors (highland: 201, 95.7%; lowland: 201, 95.7%) when encountering Anna's condition. Turning to local nurses was also a preferred option (highland: 130, 61.9%; lowland: 94, 44.8%). Only 7 (1.7%) CMs in the lowlands would not seek help. This reveals a notable discrepancy between participants' intended and actual help-seeking behaviors.

Explaining B-IPQ scores

CMs obtained a mean B-IPQ score of 23.4 (SD 2.1), with 23.1 (SD 2.2) in the highlands and 23.7 (SD 1.9) in the lowlands. Univariable and multivariable linear regression results for B-IPQ scores are shown in Table 3. In the univariable analyses, longer duration of education, unemployment, and living in the lowlands were significantly associated with higher B-IPQ scores ($p<0.05$). All associations were still significant in the multivariable model ($p<0.05$) (Table 3).

LCA model

The LCA model characteristics are shown in Table 4. The model with two classes (model 2) was considered as the best fitting model, with the lowest BIC and a high relative entropy value, indicating high certainty of classification. Figure 1 depicts the conditional item response probabilities for B-IPQ items in the two classes, with 49.3% of population share in class 1 and 50.7% in class 2. Overall, CMs in class 1 appeared to have a more negative perception about the CLD consequence, symptoms, concern and emotion, whereas those in class 2 tended to perceive CLD timeline, treatment and understanding more negatively (Figure 2). T-tests showed significant differences in all B-IPQ items between the two classes ($p<0.05$) except for control ($p=0.67$). Class comparison of participant characteristics was shown in Appendix 3. CMs in the highlands were more likely to belong to class 1 ($\chi^2=5.95$, $p=0.01$). No other factors

were significantly related to class membership (Appendix 3).

Table 3 Univariable and multivariable regression analyses for B-IPQ scores

Variables	Categories	B-IPQ[a] scores (M, SD)	Univariable regression			Multivariable regression		
			b (95% CI)	*β*	*p*	*b* (95% CI)	*β*	*p*
Age in years		23.4, 2.1	-0.00 (-0.02, .01)	-0.01	.77			
Gender	Male	23.2, 2.1	Reference					
	Female	23.5, 2.0	0.38 (-0.02, 0.78)	0.09	.06			
Education in years			0.11 (0.02, 0.20)	0.11	.021*	0.10 (0.00, 0.19)	0.10	.045*
Occupation	Unemployed	23.6, 1.9	Reference			Reference		
	Employed	23.1, 2.3	-0.49 (-0.89, -0.09)	-0.12	.016*	-0.48 (-0.87, -0.08)	-0.11	.018*
Setting	Highland	23.1, 2.2	Reference			Reference		
	Lowland	23.7, 1.9	0.59 (0.20, 0.99)	0.14	<.01*	0.52 (0.13, 0.92)	0.13	.01*
Smoking status	No smoking	23.4, 2.1	Reference					
	Currently smokes	23.5, 1.9	0.10 (-0.49, 0.69)	0.02	.73			
	Previously smoked	23.3, 2.1	-0.13 (-0.67, 0.41)	-0.02	.64			
Household risk behavior scores in summer			-0.02 (-0.18, 0.15)	-0.01	.82			
Household risk behavior scores in winter			-0.01 (-0.33, 0.31)	-0.00	.96			

a: brief Illness Perception Questionnaire.

*: $p<0.05$.

Table 4 Latent class analysis model characteristics for community members

Classes	LL[a]	BIC[b]	AIC[c]	Parameters	Entropy	Relative entropy	Class membership[d]
1	-3164.715	6474.396	6377.429	24	7.535	1.00	100%
2	-3003.726	6303.424	6105.452	49	7.162	0.975	1: 49%
							2: 51%
3	-2946.602	6340.183	6041.204	74	7.026	0.985	1: 33%
							2: 52%
							3: 15%
4	-2913.16	6424.304	6024.319	99	6.945	0.949	1: 44%
							2: 28%
							3: 9%
							4: 19%
5	-2894.947	6538.886	6037.894	124	6.887	0.965	1: 23%
							2: 24%
							3: 8%
							4: 37%
							5: 7%

a: Maximum log-likelihood.

b: Bayesian Information Criterion.

c: Akaike Information Criterion.

d: Values represent estimated population class shares.

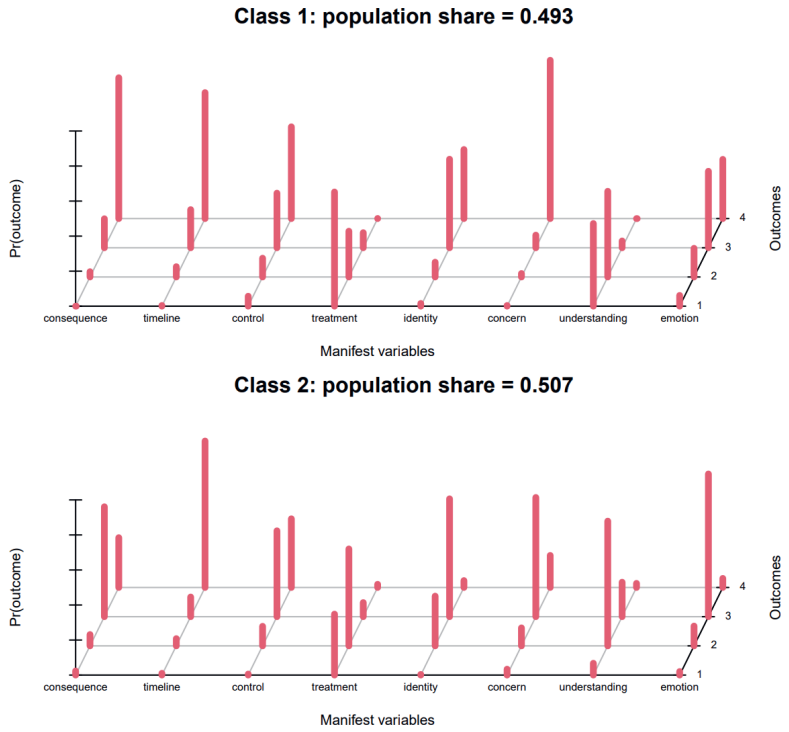


Figure 1 Conditional item response probabilities for B-IPQ items in both classes

Discussion

Main findings

Building on previous findings of the FRESHAIR project, this mixed-method study offers novel and more detailed insights into beliefs, perceptions and behaviors of community members (CMs) regarding CLD in the highlands and lowlands Kyrgyzstan. These findings can provide contextual evidence to inform future implementation research in other low-resource settings or LMICs. In our study, we found that misperceptions and misbeliefs existed regarding CLD and its causes, along with prevalent smoking, cooking and heating with risk fuels and limited ventilation, delayed help-seeking behaviors. These beliefs, perceptions, and behaviors were shaped by socioeconomic, cultural and policy-related factors. Additionally, our results showed that CMs with longer duration of education, being unemployed, and living in the lowlands tended to have more negative CLD beliefs and perceptions. LCA further identified two subgroups with different B-IPQ profiles: 49% of CMs in class 1 had more negative perceptions in the B-IPQ consequence, symptoms, concern and emotion,

while 51% in class 2 perceived more negatively in the B-IPQ timeline, treatment and understanding. Highlanders were more likely to be in class 1 while lowlanders in class 2.

Comparison with prior research

The misperceptions and misbeliefs about CLD indicate a limited understanding of CLD among CMs in Kyrgyzstan. This finding aligns with the main results of the FRESHAIR project conducted in other low-resource settings, including Uganda, Greece, Vietnam and a Roma camp [12], where CLD symptoms were also perceived as infectious conditions. Comparable findings were reported in a qualitative study [33] and a mixed-method study [34] in China, both of which highlighted gaps in awareness and understanding of CLD. In our study, the term COPD was unfamiliar to many CMs, and knowledge about asthma symptoms was also inaccurate, suggesting the absence of the targeted health education and promotion on CLD. Local health campaigns in Kyrgyzstan seemed to place greater emphasis on infectious diseases such as tuberculosis, than on chronic conditions like CLD. As a result, symptoms associated with CLD may be overlooked or misinterpreted through the lens of infectious diseases. To some extent, this reflects the existing public health priorities on infectious diseases and insufficient effectiveness of health educational campaigns promoting knowledge of CLD [35]. Contributing CLD condition to cold and weather might be because of the distinctive geography and climate in Kyrgyzstan, as long-term residence at high altitude and low temperature exposure both can affect pulmonary function [36], producing symptoms similar to CLD. This may lead local people to normalize coughing and shortness of breath, therefore obscuring the recognition of CLD.

In our study, two latent subgroups were identified with different B-IPQ profiles. Previous studies using B-B-IPQ in CLD have reported similar domain-specific patterns. For example, Dutch COPD patients had better health-related quality of life when experiencing fewer symptoms, less consequences, fewer emotional impacts and having a greater understanding of the disease [37]. In China, Liu et al [38] reported inhaler adherence is also different in COPD patients across different levels of B-IPQ control, treatment, understanding emotions. This suggests that differences in B-IPQ scores between subgroups can be useful for designing tailored interventions in the future.

Our results suggest that socio-economic position (SEP) — including duration of education, employment status, and income —is associated with CMs' beliefs, perceptions and behaviors regarding CLD. Lower SEP is typically associated with more negative and severe illness perceptions in high-income countries (HICs) [39, 40], but we found longer education duration was associated with more negative perceptions.

This illustrates a different role of SEP between HICs and LMICs. A potential explanation might be that individuals with higher education are more exposed to health information [41], therefore have a better understanding of the chronic and irreversible nature of CLD, raising greater concerns and perceived severity. In our study, unemployed individuals perceived CLD more negatively partly due to their vulnerability and lack of coping strategies, along with more emotional impact such as depression and anxiety [42]. The prevalent smoking among nomadic pastoralists during herding may also be explained by their lower SEP, including limited access to education [43] and chronic poverty in remote areas [44]. Moreover, income or financial constraint emerged as a recurring factor that shaped CLD-related behaviors in our study, including cooking and heating with risk fuels, and help-seeking. For instance, participants preferred to use biomass fuels mainly because of the high cost of clean energy, despite having access to electricity. Another study also pointed out additional financial barriers to the implementation of renewable energy supply in Kyrgyzstan, such as the uninsulated and aged building stock [45]. In terms of help-seeking, lower income limits the ability to seek timely and high-quality medical care. This finding aligns with a cross-sectional study from Brazil, which showed an evident disparity in the access to and quality of care services across socio-economic groups [46].

Cultural factors, including gender norms, ethnic identity and practice of traditional remedies, shaped people's beliefs, perceptions and behaviors regarding CLD among CMs. Culturally, CMs perceived male smoking as normal while female smoking was stigmatized. They believed that mothers played a larger role during early childhood whereas fathers appeared to become more prominent role models for smoking when kids grew older. The traditional gender norms, mirrors findings from Southeast Asia, where smoking is commonly associated with masculinities [12, 47]. The difference in help-seeking behaviors also underscores the cultural context. For example, Kyrgyz ethnicity with nomadic background appeared less likely to seek medical care compared to ethnic Russians. Similarly, another study reported that African American and Hispanic participants were more likely to receive mental health care for multiple sclerosis compared to white and Non-Hispanic participants [48]. The traditional remedies for respiratory health in Kyrgyzstan, which have also been used for centuries in Asia [49], Africa [50] and Eastern Europe [51], underscore the need for culturally sensitive health education. Given that the efficacy and safety of these remedies usually lack scientific validation[50] and evidence-based guidelines [52], it is necessary to integrate rigorously evaluated traditional knowledge into public health strategies.

Our findings also indicate policy shortcomings in CLD prevention and care. The

prevalence of smoking, especially among men and adolescents, points to the need to accelerate the local enforcement of tobacco control policies and sales regulations, as supported by the latest report on the tobacco epidemic in Kyrgyzstan [53] and a global implementation research targeting adolescents' tobacco exposure in disadvantaged populations[54]. Regarding the clean energy adoption, Kedar et al. described multiple challenges in the local context, such as affordability, limited availability, old infrastructure, and heat loss [45]. Knowledge and beliefs about the innovation, external policy and incentives also matter, according to an umbrella review [55]. These highlight the importance of policies aimed at improving energy infrastructure and promoting sustainable energy transitions. Furthermore, the easy accessibility of antibiotics without prescription reflects broader weakness of pharmaceutical regulations, which may contribute to inappropriate use and antimicrobial resistance [56]. Reported barriers to healthcare, such as long travel distance to healthcare facilities, shortage of HCPs and disparities in care quality between state and private hospitals, reflect underlying health inequalities. These inequalities exist both between and within HICs and LMICs, and addressing them requires organized and systematic health planning and policy efforts [57].

Implications and Recommendations

The misperceptions about CLD underscore a need for targeted educational interventions in practice. Public health campaigns should focus on increasing awareness of CLD, especially its chronic nature, multiple causes, such as smoking and HAP, and early warning signs. To improve the effectiveness of health campaigns, joint planning and implementation, sharing of information systems, and demand creation and community-based engagement strategies among stakeholders were recommended [58]. The current B-IPQ profiles between two subgroups can help inform the design of context-specific implementation strategies tailored to different populations. To effectively change CM's risk behaviors and promote actions, behavioral change techniques should be incorporated in health interventions [59]. Given the existing use of local educational tools like posters, brochures and lectures, we recommend the integration of digital technologies into health education efforts as digital health education demonstrated a promising feasibility, usability and user satisfaction to improve the awareness [60]. Involving the community and relevant stakeholders to co-create educational materials with plain language and illustrations also has been proven feasible and effective in LMICs [61].

For policymakers, it is essential to implement gender-sensitive, community-supported smoking cessation programs [62] and to strengthen tobacco sales regulations.

Improving energy infrastructure, promoting affordable and sustainable clean energy should also be prioritized, aligning with the Sustainable Development Goals [63]. To reduce the health inequality stemming from limited healthcare affordability and accessibility, coordinated efforts are required, such as expanding healthcare services, improving healthcare service delivery, training and retaining qualified HCPs in remote areas. For future research, we recommend further evaluation studies to assess the effectiveness of interventions on CLD awareness and behavioral change. More studies are also warranted on the diagnosis, management and self-management of CLD in primary care in Kyrgyzstan and other LMICs [64].

Limitations and strengths

This study has several limitations. First, its cross-sectional design limits causal interpretations. Second, as data were collected in 2016, the findings may have limited relevance to the current infrastructural and systemic context. Third, the findings should be extrapolated with caution due to the sampling methods, and the qualitative findings are not generalizable by nature. Nevertheless, this study provides nuanced and context-specific insights into beliefs, perceptions and behaviors of CM regarding CLD in Kyrgyzstan. The combination of qualitative and quantitative methods complemented each other, enabling a more comprehensive and in-depth understanding of the barriers in primary care in the local context and informing future implementation research. Moreover, the use of LCA identified distinct subgroups based on B-IPQ scores, which cannot be captured by regression analyses alone.

Conclusion

Misbeliefs and misperceptions in chronic lung diseases existed among community members in Kyrgyzstan, alongside prevalent smoking, household risk behaviors, and a pattern of delayed help-seeking. These beliefs, perceptions, and behaviors were shaped by socioeconomic, cultural and policy-related factors. Community members with longer duration of education, being unemployed and living in the lowlands held more negative disease perceptions. There were two subgroups with different B-IPQ profiles: class one with more negative perceptions in the consequence, symptoms, concern and emotion, while class two perceived more negatively in the timeline, treatment and understanding, which can be used for tailored interventions in different populations. These insights provide context-specific evidence to inform future implementation research aimed at improving CLD awareness, promoting behavioral change and strengthening primary care in Kyrgyzstan and potentially other low- and middle-income countries.

Abbreviations

AIC: Akaike Information Criterion
BIC: Bayesian Information Criterion
CLD: chronic lung disease
CM: community member
COPD: chronic obstructive pulmonary disease
FRESHAIR: Free Respiratory Evaluation and Smoke exposure reduction by primary Health cAre Integrated gRoups
HCP: healthcare professional
HIC: high-income country
KI: key informant
LCA: latent class analysis
LL: likelihood ratio test
LMIC: low- and middle-income country
NCD: non-communicable disease
SEP: socioeconomic position

Appendixes

Appendix 1 Number of filed activities in quantitative and qualitative data collection

	Highland		Lowland		Total
	CMs	KIs	CMs	KIs	Total
Interviews	2	4	-	2	8
Focus groups	3	-	8	2	13
Questionnaires	210	-	210	-	420

Appendix 2 Perceived causes checked by community members

Causes	Highland (n, %) (N=210) (strongly) agree	Lowland (n, %) (N=210) (strongly) agree
Stress or worry	154, 73.3	130, 61.9
It runs in the family	158, 75.2	158, 75.2
A germ or virus	177, 84.3	190, 90.5
Kitchen smoke	149, 71.0	132, 62.9
Diet or eating habits	150, 71.4	124, 59.0
Chance or bad luck	64, 30.5	53, 25.2
Poor medical care in the past	145, 69.0	169, 80.5
Pollution in the environment	188, 89.5	193, 91.9
Family problems or worries	125, 59.5	120, 57.1
Overwork	105, 50.0	98, 46.7
Ageing	125, 59.5	130, 61.9
Dust	185, 88.1	180, 85.7
Alcohol	139, 66.2	141, 67.1
Smoking	206, 98.1	205, 97.6
Second hand smoke	189, 90.0	191, 91.0
Witchcraft	70, 33.3	74, 35.2
The weather	164, 78.1	174, 82.9
Spirits	41, 19.5	57, 27.1
Brought from other regions	139, 66.2	165, 78.6
An allergy	166, 79.0	160, 76.2
Lung infection or tuberculosis in the past	178, 84.8	199, 94.8
Occupational pollution	198, 94.3	196, 93.3
Smoke exposure of mother during pregnancy	174, 82.9	193, 91.9
Exercise	51, 24.3	22, 10.5

Appendix 3 Class comparison of participant characteristics after LCA

Variable	Categories	Class 1 (n=212)	Class 2 (n=208)	Statistics
Gender, n (%)	Male	83, 39.2	102, 49.0	
	Female	129, 60.8	106, 51.0	$\chi^2(1)=3.77$, $p=0.052$
Age, mean (SD)		46.7, 13.4	47.3, 13.2	t (418)=-0.50, p =0.62
Education in years, median (IQR)		11.0, 2.0	11.0, 1.3	W=23917, p=0.12
Occupation, n (%)	Unemployed	119, 56.1	118, 56.7	
	Employed	93, 43.9	90, 43.2	$\chi^2(1)=0.00$, $p=0.98$
Setting, n (%)	Highland	119, 56.1	91, 43.8	
	Lowland	93, 43.9	117, 56.2	$\chi^2(1)=5.95$, $p=0.01$*
Smoking status, n (%)	No smoking	153, 72.2	137, 65.9	
	Currently smokes	25, 11.8	33, 15.9	
	Previously smoked	34, 16.0	38, 18.3	$\chi^2(2)=2.17$, $p=0.34$
Household risk behavior scores in summer, median (IQR)		6.0, 1.0	5.0, 1.0	W=23822, p=0.12
Household risk behavior scores in winter, median (IQR)		7.2, 0.7	7.1, 0.5	W=22949, p=0.20

*: p <0.05.

References

1. Chronic lung disease. https://www.cancer.gov/publications/dictionaries/cancer-terms/def/chronic-lung-disease. Accessed 25 June 2024.
2. Yang IA, Jenkins CR, Salvi SS. Chronic obstructive pulmonary disease in never-smokers: risk factors, pathogenesis, and implications for prevention and treatment. The Lancet Respiratory medicine. 2022;10(5):497-511.
3. Global Initiative for Asthma. https://ginasthma.org/. Accessed 06 December 2023 2023.
4. Global Initiative for Chronic Obstructive Lung Disease. https://goldcopd.org/. Accessed 06 December 2023.
5. Adeloye D, Song P, Zhu Y, Campbell H, Sheikh A, Rudan I, et al. Global, regional, and national prevalence of, and risk factors for, chronic obstructive pulmonary disease (COPD) in 2019: a systematic review and modelling analysis. The Lancet Respiratory medicine. 2022;10(5):447-58.
6. Meghji J, Mortimer K, Agusti A, Allwood BW, Asher I, Bateman ED, et al. Improving lung health in low-income and middle-income countries: from challenges to solutions. The Lancet. 2021;397(10277):928-40.
7. Tabyshova A, Hurst JR, Soriano JB, Checkley W, Wan-Chun Huang E, Trofor AC, et al. Gaps in COPD Guidelines of Low- and Middle-Income Countries: A Systematic Scoping Review. Chest. 2021;159(2):575-84.
8. Rossaki FM, Hurst JR, van Gemert F, Kirenga BJ, Williams S, Khoo EM, et al. Strategies for the prevention, diagnosis and treatment of COPD in low- and middle- income countries: the importance of primary care. Expert Rev Respir Med. 2021;15(12):1563-77.
9. Gould GS, Hurst JR, Trofor A, Alison JA, Fox G, Kulkarni MM, et al. Recognising the importance of chronic lung disease: a consensus statement from the Global Alliance for Chronic Diseases (Lung Diseases group). Respir Res. 2023;24(1):15.
10. Cragg L, Williams S, Chavannes NH. FRESH AIR: an implementation research project funded through Horizon 2020 exploring the prevention, diagnosis and treatment of chronic respiratory diseases in low-resource settings. NPJ primary care respiratory medicine. 2016;26:16035.
11. Brakema EA, Vermond D, Pinnock H, Lionis C, Kirenga B, An PL, et al. Implementing lung health interventions in low- and middle-income countries: a FRESH AIR systematic review and meta-synthesis. Eur Respir J. 2020;56(1).
12. Brakema EA, van der Kleij R, Poot CC, An PL, Anastasaki M, Crone MR, et al. Mapping low-resource contexts to prepare for lung health interventions in four countries (FRESH AIR): a mixed-method study. Lancet Glob Health. 2022;10(1):e63-e76.
13. Habib GMM, Uzzaman N, Rabinovich R, Akhter S, Ali M, Sultana M, et al. Exploring the perceptions of patients with chronic respiratory diseases and their insights into pulmonary rehabilitation in Bangladesh. J Glob Health. 2024;14:04036.
14. Ingenhoff R, Robertson N, Munana R, Bodnar BE, Weswa I, Sekitoleko I, et al. Challenges to Implementation of Community Health Worker-Led Chronic Obstructive Pulmonary Disease (COPD) Screening and Referral in Rural Uganda: A Qualitative Study using the Implementation Outcomes Framework. Int J Chron Obstruct Pulmon Dis. 2023;18:2769-83.
15. Kyrgysztan. https://www.cia.gov/the-world-factbook/countries/kyrgyzstan/. Accessed 25

June 2024.
16. Ahmedov M, Nguyen HTH, Postolovska I, Sargaldakova A. Assessing Quality of Care in the Kyrgyz Republic: Quality Gaps and Way Forward. 2020.
17. Tabyshova A, Estebesova B, Beishenbekova A, Sooronbaev T, Brakema EA, Chavannes NH, et al. Clinical Characteristics, Treatment Patterns and Economic Burden of COPD in Kyrgyzstan: A FRESH AIR Study. Int J Chron Obstruct Pulmon Dis. 2021;16:2833-43.
18. Sydykov A, Petrovic A, Maripov AM, Gredic M, Bermes DG, Kushubakova N, et al. Circulating Microparticles Are Differentially Increased in Lowlanders and Highlanders with High Altitude Induced Pulmonary Hypertension during the Cold Season. Cells. 2022;11(19).
19. Brakema EA, Tabyshova A, Kasteleyn MJ, Molendijk E, van der Kleij R, van Boven JFM, et al. High COPD prevalence at high altitude: does household air pollution play a role? Eur Respir J. 2019;53(2).
20. Braden K. Kyrgyzstan. Environmental Resources and Constraints in the Former Soviet Republics: Routledge; 2019. p. 307-23.
21. Improving health care. https://www.unicef.org/kyrgyzstan/improving-health-care. Accessed 15 December 2024.
22. Anna Kontsevaya JF. Implementation of a package of essential noncommunicable (PEN) disease interventions in Kyrgyzstan: evaluation of effects and costs in Bishkek after one year. WHO Regional Office for Europe; 2017.
23. Kleinman A. Patients and healers in the context of culture: An exploration of the borderland between anthropology, medicine, and psychiatry: Univ of California Press; 1980.
24. Ajzen IJOB, Processes HD. The theory of planned behavior. 1991;50(2):179-211.
25. Rosenstock IM, Strecher VJ, Becker MH. Social learning theory and the Health Belief Model. Health Educ Q. 1988;15(2):175-83.
26. Brakema EA, van der Kleij RM, Poot CC, Chavannes NH, Tsiligianni I, Walusimbi S, et al. A systematic approach to context-mapping to prepare for health interventions: development and validation of the SETTING-tool in four countries. BMJ Glob Health. 2021;6(1).
27. Beebe J. Basic Concepts and Techniques of Rapid Appraisal. Human Organization. 1995;54(1):42-51.
28. Broadbent E, Petrie KJ, Main J, Weinman J. The brief illness perception questionnaire. J Psychosom Res. 2006;60(6):631-7.
29. Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Med Res Methodol. 2013;13:117.
30. Linzer DA, Lewis JBJJoss. poLCA: An R package for polytomous variable latent class analysis. 2011;42:1-29.
31. Hickendorff M, Edelsbrunner PA, McMullen J, Schneider M, Trezise K. Informative tools for characterizing individual differences in learning: Latent class, latent profile, and latent transition analysis. Learning and Individual Differences. 2018;66:4-15.
32. Meijer E, Chavannes NH. Lacking willpower? A latent class analysis of healthcare providers' perceptions of smokers' responsibility for smoking. Patient Educ Couns. 2021;104(3):620-6.
33. Huang LM, Tan CY, Chen X, Jiang YJ, Zhou YR, Zhao H. A Qualitative Study on Illness

Perception and Coping Behaviors Among Patients with Chronic Obstructive Pulmonary Disease: Implications for Intervention. Int J Chron Obstruct Pulmon Dis. 2024;19:2467-79.
34. Song X, Hallensleben C, Li B, Zhang W, Jiang Z, Shen H, et al. Illness Perceptions and Self-Management among People with Chronic Lung Disease and Healthcare Professionals: A Mixed-Method Study Identifying the Local Context. Healthcare (Basel, Switzerland). 2022;10(9).
35. Gomes RE, Saraiva I, Morais-Almeida M. Awareness and education in lung diseases: Are we reaching the target? Pulmonology. 2022;28(5):330-2.
36. Sydykov A, Maripov A, Muratali Uulu K, Kushubakova N, Petrovic A, Vroom C, et al. Pulmonary Vascular Pressure Response to Acute Cold Exposure in Kyrgyz Highlanders. High Alt Med Biol. 2019;20(4):375-82.
37. Braden K. Environmental Resources And Constraints In The Former Soviet Republics. 2014/08/05 ed2014 Aug 3. 140 p.
38. Liu YR, Wang Y, Wang J, Wang X. Association between illness perception and adherence to inhaler therapy in elderly Chinese patients with chronic obstructive pulmonary disease. Chron Respir Dis. 2024;21:14799731241286837.
39. King R. Illness attributions and myocardial infarction: the influence of gender and socio-economic circumstances on illness beliefs. J Adv Nurs. 2002;37(5):431-8.
40. Dorner TE, Muckenhuber J, Stronegger WJ, Rasky E, Gustorff B, Freidl W. The impact of socio-economic status on pain and the perception of disability due to pain. Eur J Pain. 2011;15(1):103-9.
41. Benjamin-Garner R, Oakes JM, Meischke H, Meshack A, Stone EJ, Zapka J, et al. Sociodemographic differences in exposure to health information. Ethn Dis. 2002;12(1):124-34.
42. Navarro-Abal Y, Climent-Rodriguez JA, Lopez-Lopez MJ, Gomez-Salgado J. Psychological Coping with Job Loss. Empirical Study to Contribute to the Development of Unemployed People. Int J Environ Res Public Health. 2018;15(8).
43. Ali AIJARJHSS. Challenges of Nomadic pastoralists in availing primary education to their children, focusing on Hawd Region of Somaliland. 2019;2(2):28-47.
44. Bird K, Hulme D, Shepherd A, Moore KJCprcwp. Chronic poverty and remote rural areas. 2002(13).
45. Mehta K, Ehrenwirth M, Trinkl C, Zörner W. Mapping Potential for Improving Rural Energy Services in Kyrgyzstan: Factors for Achieving Sustainable Development Goals in the Community Context. World. 2022;3(3):586-606.
46. Nunes BP, Thume E, Tomasi E, Duro SM, Facchini LA. Socioeconomic inequalities in the access to and quality of health care services. Rev Saude Publica. 2014;48(6):968-76.
47. Kodriati N, Pursell L, Hayati EN. A scoping review of men, masculinities, and smoking behavior: The importance of settings. Glob Health Action. 2018;11(sup3):1589763.
48. Pimentel Maldonado DA, Eusebio JR, Amezcua L, Vasileiou ES, Mowry EM, Hemond CC, et al. The impact of socioeconomic status on mental health and health-seeking behavior across race and ethnicity in a large multiple sclerosis cohort. Mult Scler Relat Disord. 2022;58:103451.
49. Chen HY, Ma CH, Cao KJ, Chung-Man Ho J, Ziea E, Wong VT, et al. A systematic review and meta-analysis of herbal medicine on chronic obstructive pulmonary diseases. Evidence-

based complementary and alternative medicine : eCAM. 2014;2014:925069.
50. Tabuti JR, Lye KA, Dhillion SS. Traditional herbal drugs of Bulamogi, Uganda: plants, use and administration. J Ethnopharmacol. 2003;88(1):19-44.
51. Menkovic N, Savikin K, Tasic S, Zdunic G, Stesevic D, Milosavljevic S, et al. Ethnobotanical study on traditional uses of wild medicinal plants in Prokletije Mountains (Montenegro). J Ethnopharmacol. 2011;133(1):97-107.
52. Kim HS. Do not put too much value on conventional medicines. J Ethnopharmacol. 2005;100(1-2):37-9.
53. WHO report on the global tobacco epidemic, 2023: Country profile Kyrgyzstan. 2023.
54. Hoffman CM, Versluis A, Chirila S, Kirenga BJ, Khan A, Saeed S, et al. The FRESHAIR4Life study: Global implementation research on non-communicable disease prevention targeting adolescents' exposure to tobacco and air pollution in disadvantaged populations. NPJ primary care respiratory medicine. 2024;34(1):14.
55. Boudewijns EA, Trucchi M, van der Kleij R, Vermond D, Hoffman CM, Chavannes NH, et al. Facilitators and barriers to the implementation of improved solid fuel cookstoves and clean fuels in low-income and middle-income countries: an umbrella review. Lancet Planet Health. 2022;6(7):e601-e12.
56. Group WHOSW. Antimicrobial resistance. Bull World Health Organ. 1983;61(3):383-94.
57. Osadolor OO, Osadolor AJ, Osadolor OO, Enabulele E, Akaji EA, Odiowaya DEJJMCJoMS. Access to health services and health inequalities in remote and rural areas. 2022;10(2):70-4.
58. Jafari H, Saarlas KN, Schluter WW, Espinal M, Ijaz K, Gregory C, et al. Rethinking public health campaigns in the COVID-19 era: a call to improve effectiveness, equity and impact. BMJ Glob Health. 2021;6(11).
59. Carey RN, Connell LE, Johnston M, Rothman AJ, de Bruin M, Kelly MP, et al. Behavior Change Techniques and Their Mechanisms of Action: A Synthesis of Links Described in Published Intervention Literature. Ann Behav Med. 2019;53(8):693-707.
60. Sun C, Dai H, R MJJvdK, Li R, Wu H, Hallensleben C, et al. Digital Health Education for Chronic Lung Disease: Scoping Review. J Med Internet Res. 2025;27:e53142.
61. Brakema EA, van Gemert FA, Williams S, Sooronbaev T, Emilov B, Mademilov M, et al. Implementing a context-driven awareness programme addressing household air pollution and tobacco: a FRESH AIR study. NPJ primary care respiratory medicine. 2020;30(1):42.
62. Onwuzo CN, Olukorode J, Sange W, Orimoloye DA, Udojike C, Omoragbon L, et al. A Review of Smoking Cessation Interventions: Efficacy, Strategies for Implementation, and Future Directions. Cureus. 2024;16(1):e52102.
63. ENSURE ACCESS TO AFFORDABLE, RELIABLE, SUSTAINABLE AND MODERN ENERGY FOR ALL. https://www.globalgoals.org/goals/7-affordable-and-clean-energy/. Accessed 25 May 2025.
64. Abdel-Aal A, Lisspers K, Williams S, Adab P, Adams R, Agarwal D, et al. Prioritising primary care respiratory research needs: results from the 2020 International Primary Care Respiratory Group (IPCRG) global e-Delphi exercise. NPJ primary care respiratory medicine. 2022;32(1):6.

Chapter 3

Beliefs, perceptions and helping behaviors regarding chronic lung disease among healthcare professionals in Kyrgyzstan: a mixed-method FRESHAIR study

Chao Sun, Eline Meijer, Evelyn A. Brakema, Maamed Mademilov, Charlotte C. Poot, Talant Sooronbaev, Niels H. Chavannes, Rianne M.J.J van der Kleij, Marise J. Kasteleyn

BMC Health Services Research (under review, preprinted)

doi: 10.21203/rs.3.rs-9140844/v1

Chapter 3

Abstract

Background: Chronic lung disease (CLD) poses a large health and economic burden globally and is underdiagnosed in Kyrgyzstan. Understanding healthcare professionals' (HCPs) beliefs, perceptions and helping behaviors regarding CLD is crucial for optimizing clinical practice and improving patients' outcomes. This study aims to explore: (1) beliefs, perceptions and helping behaviors regarding CLD, (2) relations among demographics, setting (highlands vs. lowlands), illness perceptions and helping behaviors, and (3) illness perception profiles in HCPs in Kyrgyzstan.

Methods: Mixed-method study. Qualitative data were gathered through individual interviews and focus groups and analyzed using the Framework Method. Quantitative data were collected via questionnaires including demographics, the Brief Illness Perception Questionnaire (B-IPQ), and measures of helping behaviors such as diagnosis, referral, treatment and guideline adherence. Univariable and multivariable linear regression and latent class analysis (LCA) were performed.

Results: We included 8 individual interviews, 1 focus group (n=4), and 82 questionnaires. Two themes emerged: 1) misperceptions about CLD, and 2) restricted and experience-based helping behaviors due to a lack of resources, especially in the highlands. HCPs obtained a mean B-IPQ score of 23.3 (SD 2.4), suggesting a generally negative perception towards CLD. Most HCPs reported adhering to CLD guidelines (75, 91.5%) in the survey, but it seemed inconsistent in qualitative data. Regression results showed being physicians was significantly associated with higher helping behavior scores (p<0.05). No subgroups were identified by LCA based on B-IPQ scores.

Conclusion: HCPs in Kyrgyzstan demonstrated misperceptions about CLD and provided restricted and experience-based helping behaviors. Overall, HCPs held negative illness perceptions towards CLD, and physicians provided more help for CLD patients. Targeted training for HCPs and enhanced support for medical facilities are needed to strengthen CLD care in Kyrgyzstan.

Background

Chronic lung disease (CLD), primarily including chronic obstructive pulmonary disease (COPD) and asthma, affects over 80 million people worldwide [1-3]. Notably, a disproportionate burden of CLD falls on low- and middle-income countries (LMICs) [4], where evidence-based intervention strategies and further research are needed. In Kyrgyzstan, a LMIC in central Asia, data on the overall prevalence and economic burden of CLD remain limited [5]. However, a significant proportion of severe and very severe COPD patients has been reported, with potential underdiagnosis due to the limited availability of spirometers and a shortage of skilled healthcare professionals (HCPs) [6]. Furthermore, our previous FRESHAIR study found that misperceptions about CLD, smoking, household risk behaviors and delayed help seeking were prevalent among the local community members, with distinct illness perception profiles in Kyrgyz highlands and lowlands [7]. Being a landlocked and mountainous country, Kyrgyzstan faces different challenges in primary care such as limited healthcare access, medical facilities and research funding [8, 9]. Especially in the highlands with higher altitude and extreme climate [10], CLD care might be more challenging.

HCPs' illness beliefs and perceptions play an important role in shaping their clinical practice and how they interact with patients, while their helping behaviors (e.g., disease prevention, diagnosis, treatment and management) directly affect the quality of care delivered. For example, a systematic review indicates that HCP's misperceptions of medicine safety information might influence the implementation of risk communications with patients [11]. The stigma towards patients with substance use disorders among HCPs results in less personal engagement and empathy, thereby providing suboptimal health care [12]. In addition, HCPs' beliefs about their capacity to manage risks and moral views on appropriate intervention methods shape their intentions to deliver lifestyle interventions in primary care [13]. Moreover, inappropriate prescribing behaviors of HCPs have the potential to cause physical, psychological and financial harms to patients and deflect resources from social spending [14]. For instance, the overuse of antibiotics has led to the spread and persistence of antimicrobial-resistant bacteria [15], and prescribing excessive opioid was associated with increasing hospitalizations [16]. The discrepancy between HCPs' prescriptions and CLD guideline recommendations is also concerning, due to the risk of adverse effects and attributable costs [17]. These examples illustrate why understanding the beliefs, perceptions and helping behaviors of HCPs is crucial for improving health outcomes of patients and guiding the implementation of best clinical practices.

To the best of our knowledge, there are currently no studies exploring beliefs, perceptions, and helping behaviors regarding CLD among HCPs in Kyrgyzstan. This highlights a gap in understanding how HCPs perceive and respond to CLD in Kyrgyz primary care, a context with limited healthcare access. Particularly, there are evident geographical distribution imbalances in HCPs and healthcare facilities between

different areas [18], such as the highlands and lowlands, where the climate, altitude and local lifestyle vary [19]. In alignment with the Sustainable Development Goals target 3.4 – reducing premature mortality from noncommunicable diseases (NCDs) by one third by 2030 [20], we aim to provide insights into the local barriers to delivering CLD care, informing health strategies and implementation research for combating NCDs in Kyrgyzstan and other LMICs. Specifically, this study aims to explore the beliefs and perceptions held by HCPs about the symptoms, causes of CLD, and to understand their helping behaviors towards CLD patients in Kyrgyz highlands and lowlands. The key research questions are:

(1) What are the beliefs and perceptions regarding CLD among primary care HCPs in the highlands and lowlands of Kyrgyzstan?

(2) what helping behaviors do HCPs perform for CLD patients in the highlands and lowlands?

(3) what are the associations among HCPs' demographics, setting (highlands vs. lowlands), illness perceptions and helping behaviors?

(4) what illness perception profiles can be identified among HCPs?

Methods

Study design

This is an exploratory mixed-method study. Data were collected in Kyrgyzstan in May 2016, in both the highlands Naryn and the lowlands Chui. The rapid appraisal approach [21] was applied to collect qualitative and quantitative data efficiently and iteratively. Qualitative data were gathered through individual in-depth interviews and focus groups, while quantitative data were obtained using structured questionnaires to triangulate the qualitative data. The theoretical framework integrated the Theory of Explanatory Models of Illness [22], the Theory of Planned Behavior [23], and the Health Belief Model [24]. This study is a part of the FRESHAIR project [25], focusing on the prevention, diagnosis, and treatment of CLD in low-resource settings. More details of this study have been reported elsewhere [26].

Participants and sampling

HCPs involved in CLD care in communities were included, such as medical doctors, nurses, traditional healers and pharmacists. Anyone who was unable to participate due to physical or mental disabilities was excluded. For the qualitative part, purposive snowball and opportunity sampling was employed to include a diverse group regarding age, gender, profession and working experiences. The sample size was determined based on data saturation, i.e. when no new themes were emerging from the qualitative

data. For the quantitative part, a three-stage random sampling method was applied, with an expected sample of 40 HCPs per setting [26]. All eligible HCPs from the nearest medical facilities were invited.

Procedure

A multidisciplinary research team consisting of Kyrgyz and Dutch researchers conducted field activities. For qualitative data, interviews and focus groups were performed in a private room to ensure that participants could speak freely, each lasting about an hour. During each session, audio was recorded and field notes were taken by an experienced qualitative researcher and an English interpreter. For quantitative data, hard copies of questionnaires were distributed to participants. Prior to formal investigation, a pilot test for the feasibility and acceptability of the questionnaire was conducted. Daily meetings were held to conduct preliminary analyses to assess if data saturation was reached, and to adapt data collection strategies and measures.

Measures

All measures were described in the original study [26].

Background characteristics

Background characteristics were collected in both qualitative and quantitative part of the study, including age in years, sex (male/female), type of HCP (nurse/midwife/primary care physician/pulmonologist/pediatrician/feldsher), years in practice, and whether they obtained a medical degree or not (yes/no).

Interviews and focus groups

Interviews and focus groups were guided by a topic list based on the theoretical frameworks (see [26]). A vignette was introduced to HCPs presenting a woman, Anna, with typical CLD symptoms. Questions and probes related to the vignette were used to explore HCPs' beliefs, perceptions and helping behaviors regarding CLD. For example, "What would you say, is going on? And how would you call it?", "What do you think is the cause of these signs?", "What would you do?". Topic lists were tailored to each interview and focus group.

Questionnaires

Beliefs and perceptions about CLD

After presenting the same vignette, perceived prevalence of and familiarity with CLD were examined quantitatively using the following questions "Have you seen a patient

with Anna's condition in your practice during the past 12 months? (yes/no)", "Have you seen a patient with COPD/asthma in your practice during the past 12 months? (yes/no)", "Have you heard of COPD/asthma? (yes/no)". Participants were also asked to write down what condition they believed was described in the vignette.

Beliefs and perceptions about CLD were assessed using a revised version of the Brief Illness Perception Questionnaire (B-IPQ) [27]. The B-IPQ is a validated 9-item scale assessing consequence, timeline, personal control, treatment, identity, concern, understanding, emotion, and cause of disease, which is applicable to various diseases and has shown good reliability and validity [27]. Each item is rated on a 0–10 scale. After pilot testing, we adapted it to a 4-point scale (1 = not at all, 2 = slightly, 3 = fairly, 4 = very well) to make it easier to understand for participants, except for item 2 "how long do you think Anna's condition will continue" (1 = for days, 2 = for weeks, 3 = for months, 4 = for years). Item 9, originally an open-ended question about perceived causes of CLD, was replaced with 24 predefined options as we expected local participants had limited knowledge about CLD. Participants rated the extent to which they believed a factor (e.g. smoking, air pollution) could cause Anna's condition on a 5-point Likert scale (1 = strongly disagree to 5 = strongly agree). The total B-IPQ score was calculated by summing the eight scaled items, with items 3, 4, and 7 reverse-scored to ensure higher scores reflecting more negative illness perceptions, ranging from 8 to 32.

Helping behaviors regarding CLD

We assessed HCPs' helping behaviors premising they see a patient with the condition as Anna, including diagnosis ("do you perform or order a functional test when you suspect COPD/asthma" (0=no, 1=yes)), referral ("do you refer patients to someone else when you suspect COPD/asthma" (0=no, 1=yes), treatment ("do you prescribe any medication to COPD/asthma patients yourself" (0=no, 1=yes)) and guideline adherence ("do you adhere to guidelines for COPD/asthma" (0=no, 1=yes)). Total scores were calculated to quantify helping behaviors for COPD and asthma respectively, ranging from 0-4. Higher scores indicate more helping behaviors.

Data analyses

Qualitative data

For RQ1 and RQ2, the Framework Method [28] was applied to identify themes from qualitative data. Each transcript was translated into English by the local interpreters, and assigned a study ID. Coding and analyzing were conducted in ATLAS.ti 19.0 [29]. An initial set of open codes were developed inductively and deductively from 3-5

transcripts by two independent researchers. Then these codes were applied to the rest of transcripts and grouped into categories. Themes and sub-themes were developed through coding process, comparison of the data and examining patterns across transcripts. All codes, themes and the most representative quotes were discussed and reviewed by team members to achieve consensus. To ensure consistency and validity, feedback from Kyrgyz researchers was incorporated about the data reliability and interpretation.

Quantitative data

For RQ1 and RQ2, descriptive statistics were presented as frequencies and percentages, means (M) and standard deviations (SD) or medians with interquartile ranges (IQR) based on their variable types and distributions. For RQ3, univariable and multivariable linear regression analyses were conducted in SPSS 22.0 by entering demographics, setting (highland vs. lowland), and total B-IPQ scores for COPD and asthma as determinants, and helping behavior scores as the dependent outcome. The associations between demographics and B-IPQ scores was also examined with univariable and multivariable linear regression analyses. Variables that were statistically significant in univariable analyses were entered into the multivariable model simultaneously. $P<0.05$ was considered as statistically significant. For RQ4, latent class analysis (LCA) was performed on B-IPQ scores using the poLCA package [30] in R 4.4.2 [31]. Models were fitted sequentially, beginning with one class and progressively adding classes. Model selection was guided by the likelihood ratio test (LL), Bayesian Information Criterion (BIC), Akaike Information Criterion (AIC), relative entropy, and parsimony [32]. Lower LL, BIC, and AIC indicate better model fit, with BIC considered the most reliable criterion [33]. A relative entropy value greater than 0.8 was taken to reflect good classification certainty [33]. LCA models ranging from 1 to 3 classes were estimated, with a maximum of 1000 iterations, and each analysis was repeated 100 times. Default settings were applied for all other parameters.

Quantitative results were triangulated with qualitative results during interpretation.

Reflexivity

The research team comprises researchers from Kyrgyzstan, The Netherlands and China, with multidisciplinary backgrounds in respiratory medicine, general practice, psychology, public health, epidemiology, and implementation science. In this cross-cultural context, the team engaged themselves in the local community to build trust, collected data, compared data and interpretations with discussions to ensure consistency and reduce potential bias, and conducted the initial analyses. A second

group member independently conducted a subsequent around of analysis and interpreted the data based on previous findings and their professions. All analyses and interpretations were refined through discussion until consensus was achieved.

Ethics approval and consent to participate

An information letter was provided to participants prior to data collection, with an explanation of the study purpose, procedures, potential risks and benefits, data privacy and security. Participation was voluntary and could be withdrawn at any time. Informed consents were obtained from all participants. All data were pseudonymized and could be accessed by core researchers only. Ethical approval was acquired from the Leiden University Medical Centre Medical Ethical Committee (P16.063;04/15/2016) in the Netherlands and the National Centre of Cardiology and Internal Medicine in Bishkek Ethics Committee (5;03/03/2016) in Kyrgyzstan.

Results

Background characteristics

In total, we conducted one focus group (n=4; highlands=4), eight individual interviews (n=8; highlands vs. lowlands = 4 vs. 4) and collected 82 questionnaires (highlands vs. lowlands=42 vs. 40). The twelve HCPs involved in the qualitative phase were aged from 35-64 years, with 7-42 years of practice experience (missing values: n=2). Among them, 8 were nurses or feldshers (e.g., interns or assistants), with only 1 male participant. HCPs in the survey were aged 49.7 (SD 8.9) years and had 23.8 (SD 10.4) years of practice experience. Eighty (97.6%) of them were female, and 42 (51.2%) were nurses. However, only 12 (14.6%) had a medical degree, all of whom are general practitioners or primary care physicians, with most located in the highlands (8, 20.0%). A total of 61 (74.4%) HCPs reported having seen a patient with typical CLD-like conditions in the past 12 months, especially those working in the highlands (36, 85.7%). Additionally, 77 (93.9%) of HCPs had heard of COPD, and 81 (98.8%) had heard of asthma. More details can be found in Table 1.

Table 1 Background characteristics of questionnaire participants

Variables	Categories	Highland (n = 42)		Lowland (n = 40)		Total (n = 82)	
		M, SD	n, %	M, SD	n, %	M, SD	n, %
Total			42, 51.2		40, 48.8		82, 100.0
Age in years		45.7, 6.9		54.0, 9.0		49.7, 8.9	
Years in practice		20.8, 8.2		27.0, 11.6		23.8, 10.4	
Sex	Male		2, 4.8		0		2, 2.4
	Female		40, 95.2		40, 100.0		80, 97.6
Type of HCP	Nurse		26, 61.9		16, 40.0		42, 51.2
	Midwife		2, 4.8		0		2, 2.4
	GP/primary care physicians		4, 9.5		8, 20.0		12, 14.6
	Feldsher[a]		10, 23.8		16, 40.0		26, 31.7
Obtained a medical degree[b]	Yes (vs. no)		4, 9.5		8, 20.0		12, 14.6
Have seen a patient with Anna's condition in the past 12 months	Yes (vs. no)		36, 85.7		25, 62.5		61, 74.4
Have heard of COPD	Yes (vs. no)		38, 90.5		39, 97.5		77, 93.9
Have seen a COPD patient in the past 12 month	Yes (vs. no)		34, 81.0		29, 72.5		63, 76.8
Have heard of asthma	Yes (vs. no)		41, 97.6		40, 100.0		81, 98.8
Have seen an asthma patient in the past 12 month	Yes (vs. no)		30, 71.4		28, 70.0		58, 70.7

a: interns and assistants.

b: those who did not obtain a medical degree are found to be nurses and feldshers.

Beliefs, perceptions and behaviors regarding CLD (RQ1 and RQ2)

Theme 1: Misperceptions about CLD

Inaccurate identification of CLD among different respiratory diseases

HCPs showed inaccurate identification of CLD among different respiratory diseases, misclassifying symptoms as tuberculosis, bronchitis and pneumonia. For example, when asked what the disease could be in the vignette, an obstetrician mentioned: *"she*

has illness of heart and lungs…pleuritis. After the pleuritis, there can be chronic tuberculosis…" (I-5-H). Like this obstetrician, other HCPs appeared to consider the symptoms as indicating an infectious disease, despite recognizing the chronic nature. A feldsher replied: *"pneumonia, chronic bronchitis. If two lungs are involved, then, pneumonia" (I-2-H).* This demonstrated a misunderstanding and oversimplification of these two conditions by using the number of lungs affected. Another feldsher perceived the condition as serious and chronic but was unable to give a precise diagnosis due to limited knowledge: *"I think Anna has the neglected ailment, but cannot say whether it is bronchial asthma. She has the constant cough and it seems like chronic" (I-12-L)*. Additionally, HCPs had misperceptions about CLD development, such as *"COPD is the beginning stage of asthma…the signs were the same" (I-13-L)* and *"the chronic bronchitis can progress to asthma" (I-1-L).* They seemed to perceive asthma as a more severe condition than COPD and other respiratory diseases.

Attributing CLD-like condition primarily to weather, followed by smoking and air pollution

While smoking and air pollution were acknowledged as causes of CLD, greater emphasis was placed on the weather as the main cause of CLD. The obstetrician mentioned: *"this can be smoking, there are some people who can smoke one pack of cigarettes per day…there was also heat with fire in the house… biomasses, only biomasses (I-5-H)".* Similarly, a feldsher highlighted the smoke produced from burning during farming: *"the smoke from the leaves… In autumn or spring, we collect leaves and burn them, the whole village is in the smoke" (I-12-L).* However, HCPs frequently perceived the weather as a cause of Anna's condition, especially in the highlands. One participant responded: "*here even in summer it snows, the weather changes very often… or it suddenly becomes warm, and then the wind is often. The wind here influences the respiratory tract" (I-2-H).* Although they could not specify the disease, they tended to attribute this respiratory condition to the changeable weather or low temperature. Another nurse explained: *"it is very cold, the temperature can reach -50℃… when it is cold, people get a cold, then it might progress into the lungs" (I-6-H).*

These qualitative findings were supported by quantitative results. HCPs obtained a mean score of 23.3 (SD 2.4) for B-IPQ scores, suggesting a generally negative perception of CLD, with 22.9 (SD 2.5) in the highlands and 23.8 (SD 2.2) in the lowlands. Regarding the condition in the vignette, 37 (45.1%) HCPs perceived it as COPD, followed with bronchitis (30, 36.6%), asthma (17, 20.7%) and tuberculosis (16, 19.5%). Additionally, HCPs in the lowlands (12, 30.0%) viewed it as tuberculosis more frequently than those in the highlands (4, 9.5%). Figure 1 presents the potential CLD

causes checked most by HCPs. While more than 80% of HCPs viewed kitchen smoke, pollution in the environment, dust, smoking, secondhand smoke, and occupational pollution as causes of the condition in the vignette, many also tended to attribute it to a germ or virus (highland vs. lowland: 32, 76.2% vs. 33, 82.5%), the weather (38, 90.5% vs. 36, 90.0%), lung infection or tuberculosis in the past (38, 90.5% vs. 35, 87.5%) (Figure 1). Other causes can be found in Appendix 1.

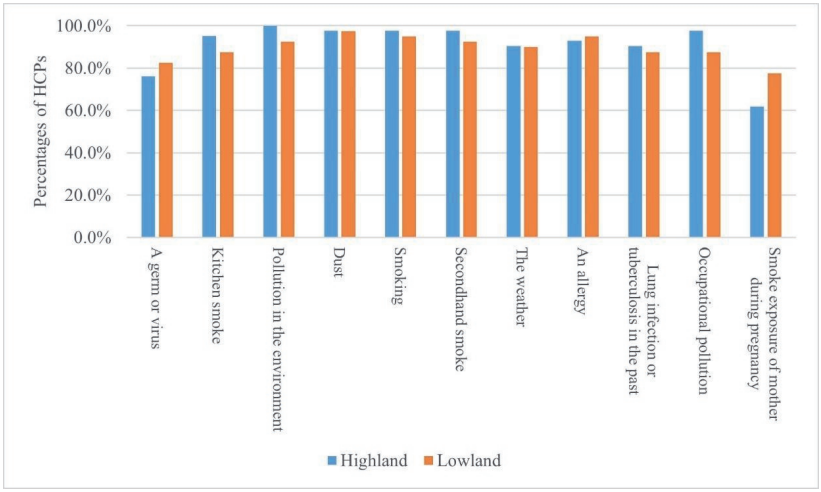


Figure 1 Potential causes of CLD-like conditions checked by HCPs

Theme 2: Restricted and experience-based helping behaviors due to lack of resources

Referring patients to better-equipped facilities after initial care

During initial care, HCPs conducted regular check-ups and provided smoking cessation advice, emphasizing the long-term consequences of smoking. A chief physician mentioned: *"when they came to the checkup, I told them when they don't give up smoking, their lungs will not be cured, they will just live with the cough" (I-7-H).* Another HCP conveyed the same message to patients: *"if young people come and they smoke, I warn them to stop smoking. I tell them about the negative effects, especially those who have children. I ask them to give it up at all or at least do not smoke at home" (I-12-L).*

In both the highlands and lowlands, HCPs tended to refer patients to better-equipped facilities after delivering initial care. One participant in the highlands mentioned: *"I listen to them with the phonendoscope, whether there exists rattling or not…I would send her to the therapist, provide the first aid, if there were many rattling sounds within the lungs, I would send her down. They could make roentgen…" (I-2-H).* This suggests

that, due to a lack of basic medical facilities for disease diagnosis, they had to send patients 'down' to the lowlands. A chief physician also confirmed the shortage of facilities: *"If the patient has a lot of rattling sounds, we will send him to the roentgen, check the phlegm for the bacteria…we don't have it… We usually send them to Kochkor… The phlegm for bacteria can be checked there" (I-7-H).* Regarding the referral place, this physician further added: "*Naryn is 150 km away, Kochkor is closer 80 km, Bishkek is further 200 km. It is better to go to Kochkor or Bishkek…if they need some observations, MRT (magnetic resonance tomography), complicated checkups, they can be sent to esophagogastroduodenoscopy (in Bishkek)" (I-2-H).* In the lowlands, however, a similar situation was noticed, as described by a nurse and a feldsher, respectively: *"I would send them to tuberculosis center in Sokuluk… we have nothing here" (I-11-L)* and *"we also do not use the peak flowmeter as we don't have it" (I-12-L)*. Despite knowing appropriate diagnostic steps, HCPs had to refer patients to another place to access essential medical tests as their own practices were limited by the equipment availability.

Treatment with antibiotics and rarely using guidelines

In general, most HCPs appeared to treat respiratory conditions based on their experiences and rarely used guidelines. To relieve respiratory symptoms, one nurse responded: *"I simply give antibiotics… Ciprofloxacin, and amoxicillin in case the lungs are affected by cold, and try to decrease the temperature…But if there is a hard cough with large amounts of phlegm, then, I am giving salbutamol…" (I-6-H).* As CLD symptoms were commonly interpreted as infections and essential diagnostic tools were lacing, antibiotics were used regardless of the actual etiology. She also reported the shortage of medications that limited their ability to provide treatment: "*we have problems with the medications, they are few, I am given a little amount of antibiotics (I-6-H)*.

When asked if they used any guidelines, one participant replied: *"no…firstly I make an observation, I don't do serious things and just write a prescription" (I-11-L).* These suggest that the diagnosis and treatment are largely based on observed symptoms rather than clinical diagnostic tools and protocols. An obstetrician responded: *"the practice is different from the theory, they are completely different, but we try to follow it… But because here we do not have the doctor, some work differently..." (I-13-L).* This suggests that there could be some protocols, but HCPs did not usually follow them. According to the survey, some HCPs mentioned it was because they had never heard of the treatment guidelines (lowlands: 2, 2.4%), or they were nurses or had not encountered such patients (highlands vs. lowlands: 3, 7.1% vs. 3, 7.5%). In addition,

one participant mentioned that due to the shortage of skilled doctors, non-physician HCPs sometimes took on prescribing and treatment tasks: *"when patients bring their appointment cards, I look and I understand that this is wrong… now doctors have poor knowledge, if you compare the doctor and the nurse, the nurse can do the work better than the doctor…It (prescribing and treatment) is not allowed to do without the doctor, but we have no doctor, so we do this by ourselves, we help people" (I-12-L).*

The total helping behavior score for COPD and asthma was 2.3 (SD 0.8), indicating HCPs provided moderate levels of help. The helping behavior characteristics of HCPs are shown in Figure 2, which complements these qualitative findings. When suspecting COPD, only a minority of HCPs reported they would perform or order a pulmonary function test (14, 17.0%) or prescribe medication themselves (21, 25.6%). Similar patterns were observed for asthma, with 13 (15.9%) performing or ordering a test and 22 (26.8%) prescribing medication. However, most of them would refer patients to other HCPs (COPD: 76, 92.7%; asthma: 80, 97.6%). Additionally, the majority of HCPs reported adhering to CLD guidelines (COPD and asthma: 75, 91.5%), which seems inconsistent with their actual practices based on qualitative data. More details are shown in Figure 2.

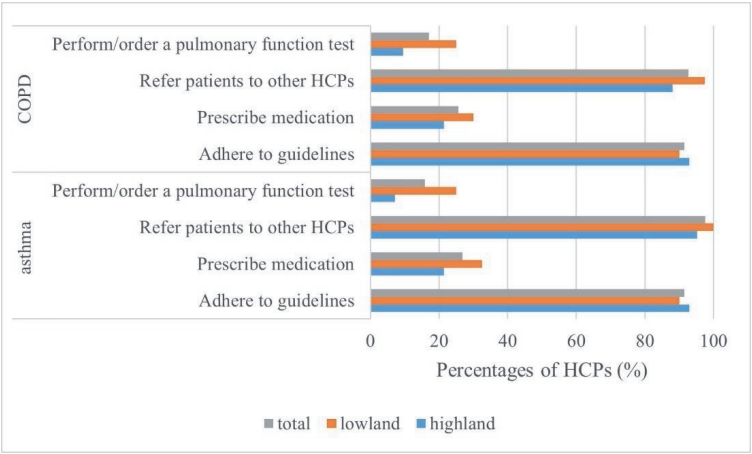


Figure 2 Helping behaviors regarding CLD among healthcare professionals

Associations among demographics, setting, illness perceptions and helping behaviors (RQ3)

Univariable linear regression results showed that older age and being physicians were positively associated with higher helping behavior scores for COPD (p<0.05) (Table 2). For asthma, being physicians was similarly associated with higher helping behavior

scores (p<0.05) (Table 2). In multivariable regression model, being physicians was uniquely associated with higher helping behavior scores for COPD (p<0.05) (Table 2). Other factors were not significantly associated with helping behavior scores (p>0.05) (Table 2). No significant associations were found between demographics and B-IPQ scores (p>0.05), see Appendix 2.

Table 2 Univariable and multivariable linear regression for helping behavior scores

Outcomes	Predictors	Categories	Univariable regression			Multivariable regression		
			b (95% CI)	*β*	*p*	*b* (95% CI)	*β*	*p*
Helping behavior scores for COPD	Age in years		0.02 (0.00, 0.04)	0.23	.04*	0.00 (-0.01, 0.02)	0.01	.71
	Years of practice		0.01 (-0.00, 0.03)	0.17	.13			
	Type of HCP	Physicians vs. nurses[a]	1.40 (1.01, 1.79)	0.63	<.01*	1.37 (0.96, 1.79)	0.21	<.01*
	Setting	Lowland vs. highland	0.31 (-0.06, 0.67)	0.18	.10			
	B-IPQ[b] scores		0.06 (-0.02, 0.14)	0.18	.11			
Helping behavior scores for asthma	Age in years		0.02 (-0.00, 0.04)	0.19	.08			
	Years of practice		0.01 (-0.01, 0.03)	0.12	.30			
	Type of HCP	Physicians vs. nurses[a]	1.43 (1.05, 1.81)	0.64	<.01*			
	Setting	Lowland vs. highland	0.31 (-0.06, 0.68)	0.18	.10			

B-IPQ scores	0.04 (-0.04, 0.11)	0.10	.36

a: includes nurses and feldshers.

b: Brief Illness Perception Questionnaire.

*: $p<0.05$.

LCA for illness perceptions (RQ4)

To identify potential subgroups of HCPs with similar illness perception characteristics, LCA were performed based on B-IPQ items. Models fitting stopped at 3 classes, suggesting adding more classes did not improve model fit substantially. However, model 1had the lowest BIC 1371.758, indicating the best statistical fit and a single latent class might adequately describe HCPs' illness perceptions. Therefore, HCPs had largely homogeneous response profiles across all B-IPQ items, details see Appendix 3.

Discussion

Main findings

This mixed-method study explored beliefs, perceptions and helping behaviors regarding CLD among HCPs in Kyrgyzstan. Our results revealed that HCPs had partial misperceptions about CLD and its causes, often struggling to distinguish it from other respiratory diseases, and mainly attributing it to infection and weather, despite recognizing smoking and air pollution as causes. Meanwhile, their helping behaviors for patients with CLD-like conditions were restricted and largely experience-based, constrained by resource shortages, and often involved referring patients to better-equipped facilities, or prescribing antibiotics. Although most HCPs reported adhering to guidelines in quantitative data, it seemed not consistent in practice from qualitative data. Overall, HCPs demonstrated negative perceptions of CLD-like conditions, suggesting that they perceived it as a severe condition, with no subgroups identified based on B-IPQ scores. Regression results indicated that physicians tended to provide more helping behaviors for COPD and asthma than nurses.

Interpretation and comparison with prior studies

HCPs' misperceptions regarding CLD, restricted and experience-based helping behaviors demonstrate a limited understanding of CLD, as well as shortages of qualified HCPs and adequate medical facilities in Kyrgyzstan. The misperceptions are in line with our previous FRESHAIR studies conducted in other low-resource settings in Uganda, Vietnam, a Roma camp [26] where infection and weather were frequently viewed as causes of CLD. Similar misperceptions were also noticed among Kyrgyz

community members [7]. However, another mixed-method study using similar vignette conducted among Chinese HCPs showed most were able to identify CLD without mentioning infectious diseases based on their working experiences or spirometry tests [34]. This reflects variations in illness beliefs and perceptions across contexts, even though both settings are LMICs. This might be related to the fact that infectious diseases such as tuberculosis, remain a challenging public health problem in Kyrgyzstan [35]. In addition, high altitude and cold exposure, can exacerbate respiratory conditions [36, 37], which may explain HCPs' misperceptions about the causes of CLD. Another possible explanation is that most HCPs in our study were nurses without a medical degree, indicating limited knowledge of CLD diagnosis and treatment. In absence of essential medical facilities, HCPs had to refer patients to other places for diagnostic tests and care, which might delay the diagnosis and treatment of CLD. These findings are consistent with previous studies from other LMICs, such as Uganda [38], Ethiopia [39] and Zambia [40], where HCPs and healthcare resource shortages are reported. The reported use of antibiotics, and the observed gap between self-reported and actual guideline practice, suggest insufficient training and limited diagnosis capacity among Kyrgyz HCPs. These may contribute to suboptimal management of CLD and increased risk of antimicrobial resistance [41].

The negative perceptions might be explained by the chronic nature and high prevalence of CLD in Kyrgyzstan [6], exposing HCPs to more CLD cases, thereby considering it as a severe condition. Based on our findings, another explanation could be that the lack of essential medical facilities hindered their ability to perform helping behaviors, leaving CLD-like conditions difficult to control and manage. The regression showed that being physicians was consistently associated with greater engagement in helping behaviors, suggesting that formal medical training may enhance clinical competency, guideline awareness, and decision-making capacity in CLD care. This aligns with prior research showing that professional training and education are necessary to ensure proactive and appropriate clinical management and treatment of CLD [38, 42]. The LCA results of our study indicate that HCPs generally held homogeneous negative perceptions towards CLD-like conditions. This differs from our findings in Kyrgyz community members [7], where highlanders and lowlanders exhibited distinct illness perception profiles. This might be because of the relatively homogeneous responses to B-IPQ items in HCPs, as LCA is suitable when distinct response patterns exists rather than minor variations in total scores [32].

Our findings reflect structural shortcomings within Kyrgyz healthcare system. Since the independence from the former Soviet Union in 1992, Kyrgyz primary care has

largely depended on retrained “family group practice” (FGP) doctors who completed short-term continuing education programs lasting only a few months [43]. In our study, nurses sometimes had to take on doctors’ duty due to a lack of doctors. This is supported by national data in 2019 showing an average of 3,902 citizens per FGP doctor, reaching 18,000 in rural areas [43]. Moreover, 61% of the FGP doctors were beyond retirement age, with 19% nearing retirement age [43]. Moreover, high rates of doctor emigration into neighboring countries, where salaries are higher, further exacerbated the brain drain [44]. Addressing the shortage of qualified HCPs and mitigating workforce attrition are critical to improving CLD care.

Implications and Recommendations

Targeted education and training should be provided to local HCPs to improve their understanding of CLD and competence in CLD care, especially regarding differential diagnosis from other respiratory diseases, appropriate treatment and adherence to guidelines. Digital health education such as computer-assisted learning, mobile learning and digital simulation-based learning is considered feasible and acceptable in different settings [45]. To address HCP shortages, expanding nursing education and roles, improving HCPs’ working conditions such as providing housing, internet, and basic medical equipment were strongly recommended by the rural family medicine residents [43]. Policymakers should prioritize strengthening healthcare infrastructure and promoting equity by investing in facilities for CLD diagnosis, treatment and management. Attention should also be given to HCPs’ workloads and salary to ensure a sustainable and effective care delivery [44]. Future studies can evaluate the effectiveness of interventions on HCPs’ illness perception and practice, and explore contextual barriers to guideline adherence to improve evidence-based CLD care. Given the financial constraints in Kyrgyzstan [7, 44], it is worthwhile to examine cost-effective strategies in a low-resource setting to maximize impact of interventions in primary care.

Limitations and strengths

Several limitations should be noted. First, self-reported data collected some time ago and responses to the vignette might have introduced bias, potentially affecting data validity and interpretation. Second, it should be extrapolated to other settings cautiously because of the small sample size, focus on HCPs, and the context-specific nature of qualitative findings. However, the integration of qualitative and quantitative findings provides nuanced and detailed insights into HCPs’ understanding of CLD and their clinical practice. These insights help identify specific gaps in misbeliefs and

misperceptions, resource-related constraints, offering valuable guidance for targeted training, guideline implementation and health system improvements in low-resource settings.

Conclusion

HCPs in Kyrgyzstan demonstrated misperceptions about CLD and provided insufficient help for CLD care, largely shaped by resource constraints and experience-based practices. Despite high self-reported adherence to guidelines, actual implementation appeared weak. Overall, HCPs held negative illness perceptions towards CLD, and physicians performed more helping behaviors. Targeted training for HCPs and enhanced support for medical facilities are needed to strengthen CLD care. Future studies should implement and evaluate interventions on improving HCPs' illness perceptions and clinical practice in Kyrgyzstan.

Abbreviations

AIC: Akaike Information Criterion
BIC: Bayesian Information Criterion
CLD: chronic lung disease
COPD: chronic obstructive pulmonary disease
FGP: family group practice
FRESHAIR: Free Respiratory Evaluation and Smoke exposure reduction by primary Health cAre Integrated gRoups
HCP: healthcare professional
HIC: high-income country
LCA: latent class analysis
LL: likelihood ratio test
LMIC: low- and middle-income country
NCD: non-communicable disease

Appendixes

Appendix 1 Potential causes of CLD-like conditions checked by HCPs

Causes	Highland (n, %) (N=42) (strongly) agree	Lowland (n, %) (N=40) (strongly) agree
Stress or worry	25, 59.5	29, 72.5
It runs in the family	28, 66.7	29, 72.5
A germ or virus	32, 76.2	33, 82.5
Kitchen smoke	40, 95.2	35, 87.5
Diet or eating habits	31, 73.8	26, 65.0
Chance or bad luck	13, 31.0	10, 25.0
Poor medical care in the past	22, 52.4	25, 62.5
Pollution in the environment	42, 100.0	37, 92.5
Family problems or worries	25, 59.5	29, 72.5
Overwork	18, 42.9	26, 65.0
Ageing	29, 69.0	25, 62.5
Dust	41, 97.6	39, 97.5
Alcohol	28, 66.7	25, 62.5
Smoking	41, 97.6	38, 95.0
Second hand smoke	41, 97.6	37, 92.5
Witchcraft	1, 2.4	7, 17.5
The weather	38, 90.5	36, 90.0
Spirits	1, 2.4	4, 10.0
Brought from other regions	13, 31.0	24, 60.0
An allergy	39, 92.9	38, 95.0
Lung infection or tuberculosis in the past	38, 90.5	35, 87.5
Occupational pollution	41, 97.6	35, 87.5
Smoke exposure of mother during pregnancy	26, 61.9	31, 77.5
Exercise	5, 11.9	3, 7.5

Appendix 2 Univariable linear regression for B-IPQ scores

Variables	Categories	B-IPQ[a] scores (M, SD)	Univariable regression		
			b (95% CI)	*β*	*p*
Age (in years)			0.03 (-0.03, 0.09)	0.11	.33
Years of practice			0.02 (-0.04, 0.07)	0.06	.57
Type of HCP[b]	Nurses[c]	23.3, 2.3	Reference		
	Physicians	23.2, 3.0	-0.12 (-1.54, 1.29)	-0.02	.86
Setting	Highland	22.9, 2.5	Reference		
	Lowland	23.8, 2.2	0.85 (-0.20, 1.89)	0.18	.11

a: Brief Illness Perception Questionnaire.

b: includes nurses (n=68, 82.9%) and physicians (n=14, 17.1%).

c: includes nurses and feldshers.

Appendix 3 Latent class analysis model characteristics for B-IPQ scores among HCPs

Classes	LL[a]	BIC[b]	AIC[c]	Parameters	Entropy	Relative entropy	Class membership[d]
1	-632.999	1371.758	1313.997	24	7.719	1	100%
2	-581.545	1379.019	1261.089	49	7.080	0.875	1: 46%
							2: 54%
3	-560.273	1446.623	1268.545	74	6.824	0.924	1: 21%
							2: 36%
							3: 43%

a: maximum log-likelihood.

b: Bayesian Information Criterion.

c: Akaike Information Criterion.

d: values represent estimated population class shares.

Relative entropy = 1- entropy / (number of observations · ln (number of classes)).

References

1. Chronic Lung Disease. https://www.lung.org/lung-health-diseases/lung-disease-lookup/chronic-lung-disease. Accessed 11 June 2025.
2. Chronic lung disease. https://www.cancer.gov/publications/dictionaries/cancer-terms/def/chronic-lung-disease. Accessed 25 June 2024.
3. Chronic respiratory diseases: more than 80 million affected and many more undiagnosed, warns new WHO and European Respiratory Society report. https://www.who.int/europe/news/item/12-06-2025-chronic-respiratory-diseases--more-than-80-million-affected-and-many-more-undiagnosed--warns-new-who-and-european-respiratory-society-report. Accessed 20 September 2025.
4. Meghji J, Mortimer K, Agusti A, Allwood BW, Asher I, Bateman ED, et al. Improving lung health in low-income and middle-income countries: from challenges to solutions. The Lancet. 2021;397(10277):928-40.
5. Tabyshova A, Emilov B, Postma MJ, Chavannes NH, Sooronbaev T, van Boven JFM. Prevalence and Economic Burden of Respiratory Diseases in Central Asia and Russia: A Systematic Review. Int J Environ Res Public Health. 2020;17(20).
6. Tabyshova A, Estebesova B, Beishenbekova A, Sooronbaev T, Brakema EA, Chavannes NH, et al. Clinical Characteristics, Treatment Patterns and Economic Burden of COPD in Kyrgyzstan: A FRESH AIR Study. Int J Chron Obstruct Pulmon Dis. 2021;16:2833-43.
7. Sun C, Kasteleyn MJ, Brakema EA, Poot CC, van der Kleij RM, Chavannes NH, et al. Beliefs, Perceptions, and Behaviors Regarding Chronic Lung Disease in Kyrgyzstan: A Mixed-method FRESHAIR Study. 2025:2025.11. 19.25338955.
8. Improving health care. https://www.unicef.org/kyrgyzstan/improving-health-care. Accessed 15 December 2024.
9. Kyrgysztan. https://www.cia.gov/the-world-factbook/countries/kyrgyzstan/. Accessed 25 June 2024.
10. Wilson RTJMR, Development. Livestock, pastures, and the environment in the Kyrgyz Republic, central Asia. 1997:57-68.
11. Alharbi AB, Berrou I, Umaru N, Al Hamid A, Shebl NA. Factors influencing the implementation of medicine risk communications by healthcare professionals in clinical practice: A systematic review. Res Social Adm Pharm. 2023;19(1):28-56.
12. van Boekel LC, Brouwers EP, van Weeghel J, Garretsen HF. Stigma among health professionals towards patients with substance use disorders and its consequences for healthcare delivery: systematic review. Drug Alcohol Depend. 2013;131(1-2):23-35.
13. Laws RA, Kemp LA, Harris MF, Davies GP, Williams AM, Eames-Brown R. An exploration of how clinician attitudes and beliefs influence the implementation of lifestyle risk factor management in primary healthcare: a grounded theory study. Implement Sci. 2009;4:66.
14. Patey AM, Fontaine G, Francis JJ, McCleary N, Presseau J, Grimshaw JM. Healthcare professional behaviour: health impact, prevalence of evidence-based behaviours, correlates and interventions. Psychol Health. 2023;38(6):766-94.
15. Davies J, Davies D. Origins and evolution of antibiotic resistance. Microbiol Mol Biol Rev. 2010;74(3):417-33.
16. Fernandes K, Martins D, Juurlink D, Mamdani M, Paterson JM, Spooner L, et al. High-

Dose Opioid Prescribing and Opioid-Related Hospitalization: A Population-Based Study. PLoS One. 2016;11(12):e0167479.
17. Alabi FO, Alkhateeb HA, Zibanayi MT, Garces J, DeBarros KM, Barletti PSB, et al. The adherence to and utility of the Global Initiative for Chronic Obstructive Lung Disease guidelines for treating COPD among pulmonary specialists: a retrospective analysis. BMC Pulm Med. 2023;23(1):216.
18. Saltanat Moldoisaeva MK, Aigul Sydykova, Elvira Muratalieva, Meder Ismailov, Joana Madureira Lima, Bernd Rechel. Kyrgyzstan Health System Review 20222022.
19. Pryde P. Environmental resources and constraints in the former Soviet Republics: Routledge; 2019.
20. Noncommunicable diseases. https://www.who.int/data/gho/data/themes/topics/indicator-groups/indicator-group-details/GHO/sdg-target-3.4-noncommunicable-diseases-and-mental-health. Accessed 23 August 2025.
21. Beebe J. Basic Concepts and Techniques of Rapid Appraisal. Human Organization. 1995;54(1):42-51.
22. Kleinman A. Patients and healers in the context of culture: An exploration of the borderland between anthropology, medicine, and psychiatry: Univ of California Press; 1980.
23. Ajzen IJOB, Processes HD. The theory of planned behavior. 1991;50(2):179-211.
24. Rosenstock IM, Strecher VJ, Becker MH. Social learning theory and the Health Belief Model. Health Educ Q. 1988;15(2):175-83.
25. Cragg L, Williams S, Chavannes NH. FRESH AIR: an implementation research project funded through Horizon 2020 exploring the prevention, diagnosis and treatment of chronic respiratory diseases in low-resource settings. NPJ primary care respiratory medicine. 2016;26:16035.
26. Brakema EA, van der Kleij R, Poot CC, An PL, Anastasaki M, Crone MR, et al. Mapping low-resource contexts to prepare for lung health interventions in four countries (FRESH AIR): a mixed-method study. Lancet Glob Health. 2022;10(1):e63-e76.
27. Broadbent E, Petrie KJ, Main J, Weinman J. The brief illness perception questionnaire. J Psychosom Res. 2006;60(6):631-7.
28. Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Med Res Methodol. 2013;13:117.
29. ATLAS.ti Scientific Software Development GmbH. https://atlasti.com. Accessed.
30. Linzer DA, Lewis JBJJoss. poLCA: An R package for polytomous variable latent class analysis. 2011;42:1-29.
31. R: A Language and Environment for Statistical Computing. https://www.R-project.org/. Accessed 05 March 2025.
32. Hickendorff M, Edelsbrunner PA, McMullen J, Schneider M, Trezise K. Informative tools for characterizing individual differences in learning: Latent class, latent profile, and latent transition analysis. Learning and Individual Differences. 2018;66:4-15.
33. Meijer E, Chavannes NH. Lacking willpower? A latent class analysis of healthcare providers' perceptions of smokers' responsibility for smoking. Patient Educ Couns. 2021;104(3):620-6.

34. Song X, Hallensleben C, Li B, Zhang W, Jiang Z, Shen H, et al. Illness Perceptions and Self-Management among People with Chronic Lung Disease and Healthcare Professionals: A Mixed-Method Study Identifying the Local Context. Healthcare (Basel, Switzerland). 2022;10(9).
35. HIV and TB Overview: Kyrgyzstan. https://www.cdc.gov/global-hiv-tb/php/where-we-work/kyrgyzstan.html. Accessed 3 November 2025.
36. Kosanovic D. High Altitude-Induced Pulmonary Hypertension: Our Scientific Journey to Prove Cold Exposure Is Also an Important Cause. Pulm Circ. 2025;15(4):e70186.
37. Sydykov A, Maripov A, Muratali Uulu K, Kushubakova N, Petrovic A, Vroom C, et al. Pulmonary Vascular Pressure Response to Acute Cold Exposure in Kyrgyz Highlanders. High Alt Med Biol. 2019;20(4):375-82.
38. Robertson NM, Nagourney EM, Pollard SL, Siddharthan T, Kalyesubula R, Surkan PJ, et al. Urban-Rural Disparities in Chronic Obstructive Pulmonary Disease Management and Access in Uganda. Chronic Obstr Pulm Dis. 2019;6(1):17-28.
39. Tarekegn SM, Tadesse D, Argaw MD, Semahegn A, Taddesse L, Shifarraw S, et al. Capacity and performance of primary health care in Ethiopia: a novel mixed methods measurement in low-income country. BMC Prim Care. 2025;26(1):299.
40. Phelan H, Yates V, Lillie E. Challenges in healthcare delivery in low- and middle-income countries. Anaesthesia & Intensive Care Medicine. 2022;23(8):501-4.
41. Group WHOSW. Antimicrobial resistance. Bull World Health Organ. 1983;61(3):383-94.
42. Aldhahir AM, Alqahtani JS, AlDraiwiesh IA, Alghamdi SM, Alsulayyim AS, Alqarni AA, et al. Healthcare providers' attitudes, beliefs and barriers to pulmonary rehabilitation for patients with chronic obstructive pulmonary disease in Saudi Arabia: a cross-sectional study. BMJ Open. 2022;12(10):e063900.
43. Fonken P, Bolotskikh I, Pirnazarova GF, Sulaimanova G, Talapbek Kyzy S, Toktogulova A. Keys to Expanding the Rural Healthcare Workforce in Kyrgyzstan. Frontiers in public health. 2020;8:447.
44. Hardison C, Fonken P, Chew T, Smith B. The emergence of family medicine in Kyrgyzstan. Family medicine. 2007;39:627-33.
45. Sun C, Dai H, R MJJvdK, Li R, Wu H, Hallensleben C, et al. Digital Health Education for Chronic Lung Disease: Scoping Review. J Med Internet Res. 2025;27:e5314

Chapter 4

eHealth Literacy in the General Population: A Cross-Sectional Study in China

Chao Sun, Eline Meijer, Niels H. Chavannes, Huohuo Dai, Xiao Li, Yue Wang, Liangqiuhe Wu, Qing Zhang, Marise J. Kasteleyn

BMC Public Health 25, 211 (2025). doi: 10.1186/s12889-025-21389-0

Chapter 4

Abstract

Background eHealth literacy (eHL) is positively associated with health-related behaviors and outcomes. Previous eHL studies primarily collected data from online users and seldom focused on the general population in low- and middle-income countries (LMIC). Additionally, knowledge about factors that affect eHL is limited. Chronic lung disease (CLD) has brought a large burden in LMIC, making it a relevant example for studying eHL. This study aims to explore eHL and its associated factors within the general population of China, encompassing sociodemographic characteristics, CLD knowledge, digital access, eHealth use and attitudes towards eHealth.

Method Data were collected from November 2023 to January 2024 via online and hard-copy questionnaires among the general population in China. Descriptive analyses were performed to explore eHL, CLD knowledge, digital access, and attitudes towards eHealth at different sociodemographic levels. Univariable and multivariable regression analyses were performed to identify factors associated with eHL.

Results 439 valid questionnaires were collected. Participants demonstrated a mean eHL of 24.7±8.2 and CLD knowledge of 5.9±3.7, obtained a score of 6.9±1.8 in attitudes towards eHealth. A notable percentage of participants (45/439, 10.3%) reported no digital access, especially those aged 66+, the unemployed, retired, those with a primary school or below degree and earning ≤1500 RMB monthly. Multivariable hierarchical regression analysis showed higher eHL was uniquely associated with younger age (b=-0.10, P<.001), higher educational level (b=2.02, P<.001), higher income (b=1.10, P<.001), having digital access (b=6.35, P<.001), more frequent eHealth use (b=1.14, P<.001), and more positive attitudes towards eHealth (b=0.47, P=.003).

Conclusion Our sample from the general population in China had a relatively low eHL and CLD knowledge level, but held a positive attitudes towards eHealth. A digital divide was noticed between the elderly, low socioeconomic population and other groups. Younger age, higher educational and income level, having digital access, more frequent eHealth use and more positive attitudes towards eHealth were significantly associated with higher eHL. Efforts at both individual and systematic levels should be made to improve eHL, and promote CLD knowledge and digital access, especially in disadvantaged populations. Moreover, there is a pressing need to develop and refine national and international standards for eHL.

Introduction

eHealth literacy (eHL) is defined as the capacity to effectively seek, find, understand, and appraise health information from information and communication technology (ICT) and the ability to apply it to address health issues [1]. People with higher eHL tend to practice positive health behaviors [2], make better health decisions such as seeking web-based health information [3], and show better medication adherence and quality of life [4]. As ICT such as the internet becomes a popular source for individuals to understand their health conditions [5], possessing sufficient eHL is necessary to mitigate the risk of misinformation and achieve better health outcomes.

Sociodemographic characteristics have been widely studied as factors affecting eHL, but results vary and are inconclusive. For instance, some studies reported that male gender [6, 7], younger age [8-10], and higher educational level [10] were positively associated with eHL, while others found inverse relationships or no statistically significant associations [11, 12]. These findings suggest that the differences in eHL among socio-demographic groups may vary due to the target population and sampling methods. More importantly, a large proportion of participants lacking digital access, such as those with a low socioeconomic position (SEP), were not considered, which makes results difficult to extrapolate to the general population.

Lacking digital access may be associated with lower eHL. Previous studies have shown a significant positive correlation between eHL and computer access in healthcare professionals (HCPs) [13], and higher eHL scores are consistently associated with increased eHealth use across various populations, including transplant recipients [14], chronic rheumatic disease patients [15], nursing students [16] and cancer patients [17]. However, a considerable part of the global population cannot benefit from digital technology in healthcare due to inequity in connectivity, affordability, and accessibility [18]. As people increasingly use smartphones and health applications to monitor and manage their health [19], this disparity impedes people's access to online health information and services, limiting their ability to make informed and right health decisions. Consequently, it exacerbates the inequality between the disadvantaged populations and the more privileged individuals, contributing to the digital divide [20], which has been noticed in China [21] and other LMICs [22]. Therefore, investigating digital access and eHL is crucial for understanding the digital divide situation and mapping out future digital health initiatives effectively to reach disadvantaged populations.

Aside from digital access and eHealth use, attitude towards eHealth also plays an important role in eHL. According to a recent meta-analysis, lower eHL is associated with a negative attitude towards eHealth [23]. Negative attitudes towards eHealth primarily manifested in the disbelief in the potential of digital care, privacy concerns and lack of interest, ultimately impacting individuals' adoption and usage patterns [24], potentially affecting eHL. Conversely, positive attitudes can facilitate the adoption and effective use of eHealth. However, evidence about attitudes and eHL in low- and middle-income countries (LMIC) remains scarce in the literature.

China, as the largest LMIC, with 1.079 billion Internet users and 76.4% of the total internet penetration rate in 2023 [25], presents a fascinating landscape for studying eHL. A growing number of online platforms and social media, such as Ali Health, Dingxiang Garden, and Wechat, are emerging in China. It requires sufficient eHL to access health services efficiently and accurately. Studies have shown that individuals with a solid understanding of the symptoms, risk factors, and treatment or management guidelines of diseases are more likely to be well-educated and recognize online misinformation, which enhances their ability to navigate the internet effectively and contributes to higher eHL [26]. Conversely, eHealth-literate people tend to be more equipped with disease knowledge because they know how to effectively search for and apply evidence-based information efficiently [27, 28]. It is worth exploring the association between disease knowledge and eHL further to guide more effective patient education, ultimately, enhancing health outcomes of patients.

Chronic lung disease (CLD), mainly including chronic obstructive pulmonary disease (COPD) and asthma, has brought an enormous economic and health burden worldwide, especially in LMIC in less-developed regions [29-31], therefore making it a relevant example for eHL study. In China, CLD has become a major public health issue [32] with a significant underdiagnosis and undertreatment due to the low prevalence of spirometry use and limited conformity to clinical guidelines [33]. Despite the current severe situation of CLD, the effectiveness of educational campaigns aimed at providing the public with CLD knowledge on prevention, control and cure remains unsatisfactory [34]. Assessing CLD knowledge in the context of eHL allows for the customization of digital health content based on an individual's baseline understanding of CLD. This approach can improve the effectiveness of digital interventions for CLD. However, evidence on CLD knowledge level in general population and its association with eHL remains scarce.

Currently, studies examining eHL and its association factors are conducted globally, though results vary by region and often focus on specific populations [7, 8, 12, 17]. The availability of various eHL measurement tools, including self-reported and performance-based measurements, complicates the comparison of eHL levels across regions and populations [35, 36]. Data from a systematic review that studied eHL measurements indicates that fewer eHL studies were conducted in LMICs [35]. Studies on eHL in China mostly collected data through online surveys [37-40], which are often less accessible for groups such as individuals with a lower SEP or limited digital access. Furthermore, these studies tend to focus on specific populations, including patients [41], students [42], the elderly [43], and HCPs [44], limiting the generalizability of findings to the broader population. Moreover, few studies have explored the association between CLD knowledge, attitudes towards eHealth and eHL, which could provide insights into how knowledge and attitudes shape eHL, ultimately guiding the development of more efficient digital health interventions.

In this study, therefore, we aim to investigate eHealth literacy among the general population in China and examine the associations between socio-demographic factors, CLD knowledge, digital access, eHealth use, attitudes towards eHealth, and eHL. We addressed the following research questions in the general population in China:

RQ1: What are the levels of eHL, CLD knowledge, digital access, and attitudes towards eHealth across different sociodemographic groups?

RQ2: What are the associations between socio-demographic factors, CLD knowledge, digital access, eHealth use, attitudes towards eHealth, and eHL?

Methods

Study design

This is a cross-sectional study conducted in the general population in China. Data were collected online and offline from November 24, 2023 to January 10, 2024.

Participants

Participant recruitment took place from November 2023 to January 2024. Eligible individuals met the following criteria: 1) adults (age ≥18 years) speaking Chinese; 2) capable of understanding and responding to the online or offline questionnaire; 3) willing to participate voluntarily, with the ability to provide informed consent. Exclusion criteria included severe cognitive impairments or conditions that hindered

the ability to understand and respond to the questionnaire. Cases were considered invalid if participants checked no digital technology but they finished the questionnaire online.

Procedure

Due to the exploratory nature of this study, the sample size was not determined using a formal statistical formula. Instead, it was guided by the general rule of "at least 10 cases per variable (predictor)" for regression analyses [45]. With ten variables included — eHL, five sociodemographic characteristics, CLD knowledge, digital access, eHealth use and attitudes towards eHealth —a minimum sample size of 100 was deemed appropriate. To ensure more representativeness of the sample and robustness of the regression model, we recruited more than 100 participants. Convenience sampling was utilized during the data collection process. First, questionnaires were presented electronically on the widely used Chinese online survey platform Questionnaire Star [46] by the first author (CS). To reach a broad online audience, the survey link was shared through Wechat (CS, HD, XL, YW, LW, QZ), a popular social media platform in China. There were no regional restrictions for online recruitment. In addition, offline efforts were made to include individuals who might have limited online access or literacy. Investigators comprising bachelor and master students with medical backgrounds (XL, YW, LW) collected questionnaires face-to-face from local communities, nursing homes and pedestrians by convenience sampling in Shiyan and Wuhan, China. The selection of these locations was based on their demographic diversity and accessibility to a wide range of participants. Wuhan is the capital city of Hubei province, known for its large population and pivotal role in the economy, transportation, and education in central China. Shiyan, also located in Hubei province, is a smaller mountainous city. An online training session for investigators was given via Zoom, including an introduction to the survey, inclusion and exclusion criteria, investigation skills and cautions. Assistance was provided for participants when filling in the questionnaire if necessary. During the survey, researchers maintained a neutral stance to minimize any sense of hierarchy. Each item was clearly explained to prevent ambiguity or suggestive questions, ensuring that participants fully understood each question and provided honest answers. Answering all questions was required to avoid missing values.

Measures

We used a validated and widely used self-assessment tool eHealth Literacy Scale

(EHEALS) [47] (Cronbach's α=0.88) originally developed by Norman et al. in 2006 to assess an individual's eHL, and developed several items to measure CLD knowledge, digital access and eHealth use, and attitudes towards eHealth based on literature [13, 14, 23, 48] as there are currently no validated scales that fit the purpose of our study to measure them. A forward and backward translation to Chinese was conducted thereafter (CS and HD) for self-designed items. A pre-test was conducted (CS) with 4 participants (2 for online and 2 for offline testing) randomly selected from community residents in Wuhan before the formal data collection phase to ensure the clarity of the questionnaires. The whole completion time of these participants was recorded (70 seconds to 135 seconds), and then at least 80 seconds (70s + 10s buffer time) was considered valid. For self-designed items, language was optimized based on the collected feedback and suggestions to conform to the local customs. The complete questionnaire is presented in Appendix 1.

eHealth literacy

For this study, we used the Chinese version of the EHEALS, which comprises eight statements rated on a 5-point Likert scale, and has demonstrated robust psychometric properties (Cronbach's α=0.96) [35, 49]. Each item was scored from 1 (strongly disagree) to 5(strongly agree), resulting in a total score ranging from 8 to 40, with higher scores representing greater eHealth literacy. As there is no established norm for evaluating eHL levels, our assessments can only be based on the range of scores.

Sociodemographic characteristics

We collected the following sociodemographic variables: gender (1=male, 2 =female, 3=other), age (in years), occupation (1=housewife/man, 2=unemployed, 3=retired, 4=traditional farming and agricultural sector, 5=education or social services, 6=healthcare service, 7=Manufacturing sector, 8=transportation/construction, 9=others), highest educational level (1=primary school and below, 2= senior high school, 3=junior high school or secondary technical school, 4=college and above), personal monthly income (1=≤1500 Renminbi (RMB), 2=1501-3000 RMB, 3=3001-6000 RMB, 4=6001-9000 RMB, 5=≥9001 RMB, 6=prefer not to say) (1 RMB≈0.13 Euro, 0.14 US dollar, accessed on 20/04/2024). We recoded age as a categorical variable (1=18-25, 2=26-35, 3=36-45, 4=46-55, 5=56-65, 6=66+) to present age group differences. Occupation housewife/man and the unemployed, manufacturing and transportation/construction were merged into the categories "unemployed" and

"manufacturing/transportation/construction" respectively for the analyses due to the small sample size of these subgroups.

CLD knowledge

CLD includes different types of lung diseases, but for the purposes of this study, we focused solely on COPD and asthma, given their prevalence as the most common types. For CLD knowledge, we used some items extracted from the previous project FRESHAIR [48] — a mixed-method study exploring the prevention, diagnosis and treatment of CLD in low-resource settings based on a validated tool [50], but this is not validated as a separate questionnaire. A short story about a person named Xiulian with typical CLD symptoms was presented without mentioning CLD in the text. Participants were asked "what led to Xiulian's disease" to identify potential causes of the disease by selecting from 24 items on a 5-item Likert scale (from strongly disagree to strongly agree). Based on the Global Initiative for COPD (GOLD) 2023 [51] and the Global Initiative for Asthma (GINA) 2023 [52], we identified the following factors as causes of CLD in this questionnaire: it runs in the family, a germ or virus, kitchen smoke, pollution in the environment, ageing, dust, smoking, second-hand smoke, allergy, lung infection or tuberculosis in the past, occupational pollution, smoke exposure of the mother during pregnancy. We calculated the total scores of these factors to evaluate participants' knowledge (strongly agree and agree=1, else=0 per factor), ranging from 0 to 12. Similarly, we assessed CLD knowledge levels based on the range.

We also divided all potential causes into different categories to get a further understanding of how people perceive CLD causes: medical (i.e. it runs in the family, allergy, a germ or virus, poor medical care in the past, lung infection or tuberculosis in the past), cultural (i.e. chance or bad luck, witchcraft, spirits), environmental (i.e. kitchen smoke, pollution in the environment, dust, occupational pollution, smoke exposure of the mother during pregnancy, second-hand smoke, weather, brought from other regions), lifestyle (i.e. smoking, exercise, diet or eating habits, overwork, alcohol), others (i.e. stress or worry, family problems or worries, aging).

Digital access and eHealth use

We measured digital access with 2 items: "Do you have a digital technology (e.g. cell phone, computer, tablet)?" (1=yes, 0=no). and "Do you get an internet connection with your digital technology?" (1=yes, 0=no). Only if both were answered yes we considered participants as having digital access.

eHealth use was assessed with “Do you use digital technology to get health information” (1=yes, 0=no). If yes, type of source (1=search engine, 2=social media platforms, 3=online video platforms, 4=health websites, 5=health applications, 6=online communities and forums, 7=telemedicine services) and frequency of use (from 1=less than once a week to 5=≥6 times a week) of eHealth were recorded by asking “what kind of source do you usually use to get health information? (multiple choice)” and “How often do you use them?” (1=less than once a week, 2=once a week, 3=2-3 times a week, 4=4-5 times a week, 5=≥6 times a week).

Attitudes towards eHealth

Attitudes towards eHealth were measured with 2 statements respectively with a 5-item Likert scale (from 1=strongly disagree to 5=strongly agree), which evaluated participants’ perceived ease of use and usefulness of eHealth adapted from the Unified Theory of Acceptance and Use of Technology (UTAUT) [53]. For eHealth users who responded “yes” in eHealth use and checked “once a week” or more in frequency of use, the statements were “I consider eHealth to be easy to use” and “I believe eHealth can provide valuable health information and support”. For non-users who had no digital access or used eHealth less than once a week, they were asked “I expect eHealth to be easy to use” and “I expect eHealth can provide valuable health information and support”. Finally, a total score was calculated ranging from 2 to 10, with higher scores indicating a more positive attitude towards eHealth.

Statistical analysis

For RQ1, continuous variables were reported as means and standard deviations (SD) for Gaussian distributions. Frequencies and percentages were reported for categorical variables. Given the explorative nature of this RQ, group differences were illustrated through graphs but not statistically tested. For RQ2, we performed univariable and multivariable linear regression analyses. During regression analyses, cases where participants checked “other gender” (n=3) and preferred not to mention their income (n=19) were deleted due to the small sample size of these subgroups, which rendered them inefficient for further analysis as categorical variables. Dummy variables were generated for occupation, using education or social services (the subgroup with the largest sample size) as the reference group. First, for the univariable linear regression analysis, sociodemographic characteristics (gender, age in years, highest educational level, occupation, and income), CLD knowledge, digital access, frequency of eHealth use, attitudes towards eHealth were entered into separate regression analyses as

determinants, and eHL as a dependent outcome in all analyses. On the premise that all statistical assumptions were met, all significant predictors (P<0.05) were then entered into the hierarchical multivariable model with a predefined order: sociodemographic characteristics were entered in step 1, followed by remaining variables in step 2. All statistical analyses were conducted with SPSS 22.0.

Ethics approval and consent to participate

This study adhered to the Declaration of Helsinki. Ethical approval was acquired from the Biomedical Ethics Committee of Wuhan University before the study (registration number: WHU-LFMD-IRB2023063). For online participants, an introductory information letter was provided prior to the survey, including a detailed explanation of the study's purpose, procedures, potential risks and benefits, data privacy and security, voluntary nature. Participants can proceed to the survey only after indicating their consent by checking 'I agree' option. For offline participants, a hard copy of the same information letter and consent form were provided and explained as needed.

Results

General results

A total of 486 participants were enrolled (online: n=336; offline: n=150). After data cleaning, 47 questionnaires were excluded (completion time <80s =11, no consent =29, age<18 =4, online participants checked no digital access =3), and 439 valid questionnaires (online: 289/439, 65.8%; offline: 150/439, 34.2%) were included, comprising 255 (58.1%) females, 181 (41.2%) males and 3 (0.7%) other genders. Participants were aged between 18 and 90 years, with a mean age of 47.0 (SD 18.6). A wide range of occupational sectors was covered, with the majority in education or social services (93/439, 21.2%) (Table 1). Furthermore, 133 (30.3%) of the participants reported primary school degree as the highest attained educational level. Regarding the individual income, most participants (133/439, 30.3%) earned 3001-6000 RMB per month. Table 1 presents an overview of participants' characteristics.

Table 1 Sociodemographic characteristics of participants (n=439)

Characteristics	Categories	N	Percent (%)
Gender	male	181	41.2
	female	255	58.1
	other	3	0.7
Age (years)	18-25	67	15.3
	26-35	94	21.4
	36-45	39	8.9
	46-55	65	14.8
	56-65	97	22.1
	66+	77	17.5
Occupation	unemployed	35	8.0
	retired	85	19.4
	traditional farming and agricultural sector	69	15.7
	education or social services	93	21.2
	healthcare service	37	8.4
	manufacturing/transportation/construction	48	10.9
	others	72	16.4
Educational level	primary school and below	133	30.3
	junior high school	88	20
	senior high school/secondary technical school	67	15.3
	college and above	151	34.4
Income	≤1500 RMB	67	15.3
	1501-3000 RMB	87	19.8
	3001-6000 RMB	133	30.3
	6000-9000 RMB	81	18.5
	≥9001 RMB	52	11.8
	prefer not to say	19	4.3

Sociodemographic differences (RQ1)

eHealth literacy

Participants had a mean eHL of 24.7 out of 40 (SD 8.2). Figure 1 provides an overview of mean eHL scores across various sociodemographic characteristics. There was no evident difference in eHL between males and females. Younger participants aged 18-25 and 26-35 seemed to have higher scores than other age groups, and eHL decreased

with increasing age. Participants working in healthcare services demonstrated the highest eHL scores (mean 32.8, SD 5.3) while the retired and unemployed showed the lowest (mean 21.0, SD 8.2) (mean 21.3, SD 8.9) respectively. Additionally, eHL seemed to be increasing with increasing educational and income levels, with the highest among participants achieving a college degree and above (mean 30.6, SD 6.2) and those earning over 9001 RMB (mean 29.6, SD 6.9) monthly.

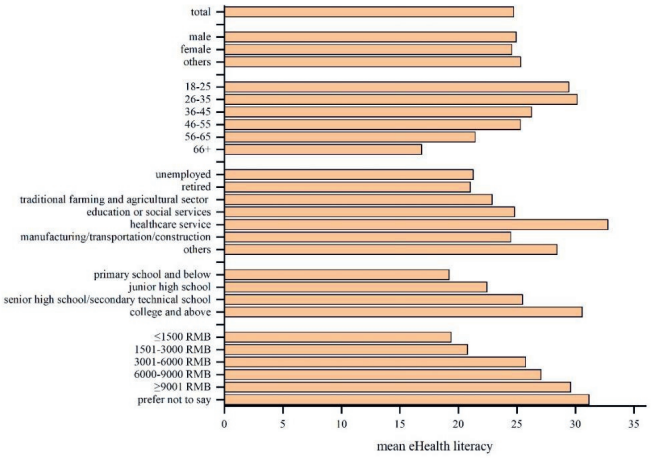


Figure 1. Mean eHealth literacy scores across different sociodemographic characteristics

CLD knowledge

The Cronbach's α of this subscale was 0.85, showing a good internal consistency of the items in the CLD knowledge subscale [54]. Overall, participants had a relatively low score (mean 5.9, SD 3.7, reference range: 0-12) on CLD knowledge, details are presented in Figure 2. A slight gender difference in CLD knowledge scores was noticed, such that females (mean 6.02, SD 3.74) seemed to score slightly higher than males (mean 5.72, SD 3.71). Participants aged 66+ scored the highest (mean 7.3, SD 3.1) compared with other age groups. Regarding occupation, participants working in healthcare services (mean 6.8, SD 3.1) and 'other' sectors (mean 7.4, SD 3.8) had higher CLD knowledge scores. With regard to socioeconomic position variables, higher scores were noticed in participants with a college degree and above, or with a relatively lower income. As shown in Figure 3, most participants checked 3 medical (101/439, 23.0%) factors and 2 lifestyle (129/439, 29.4%) factors as potential causes of CLD. In addition,

77 (17.5%) and 273 (62.2%) participants did not check any environmental or cultural factors, respectively.

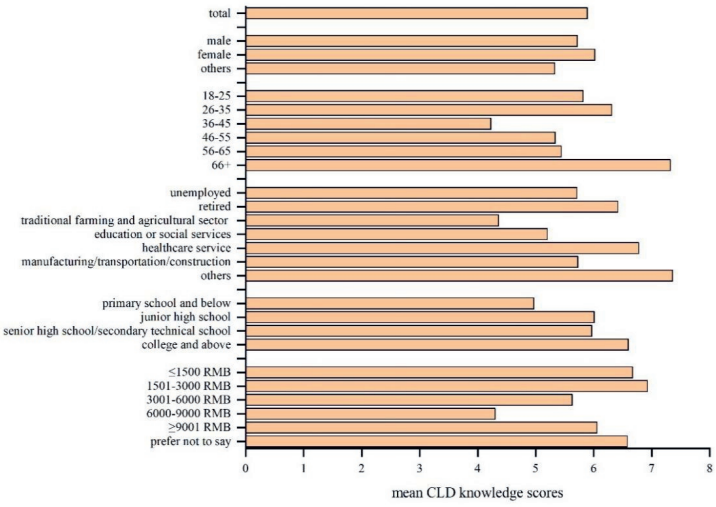


Figure 2 Mean chronic lung disease knowledge scores across different sociodemographic characteristics

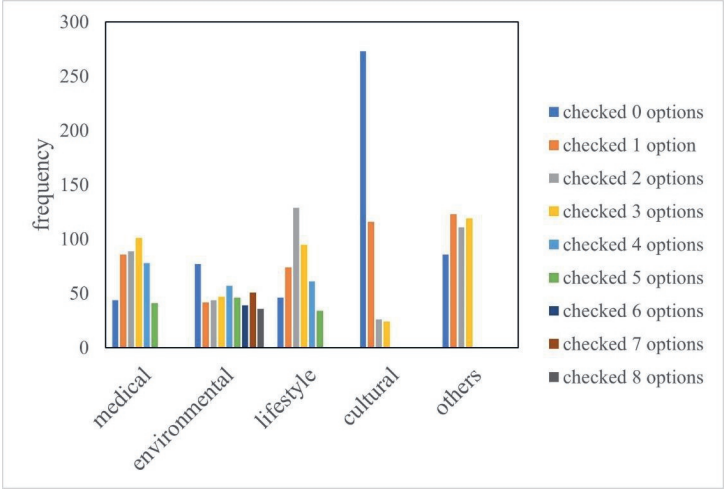


Figure 3. Potential CLD causes checked by participants

Digital access and eHealth use

The majority of participants (394/439, 89.7%) had digital access (Figure 4). However, a large proportion of participants who were aged 66+ (30/77, 39.0%), unemployed (8/35, 22.9%) or retired (16/85, 18.8%), individuals with a primary school or below degree (29/133, 21.8%%) and ≤1500 RMB income (22/67, 32.8%) had no digital access.

Regarding the type of digital technology used to search for health information, social media platforms (264/439, 60.1%), search engines (201/439, 45.8%) and health applications (197/439, 44.9%) were the most popular mediums among participants. Most of them used these 2-3 times a week (131/439, 29.8%) or less.

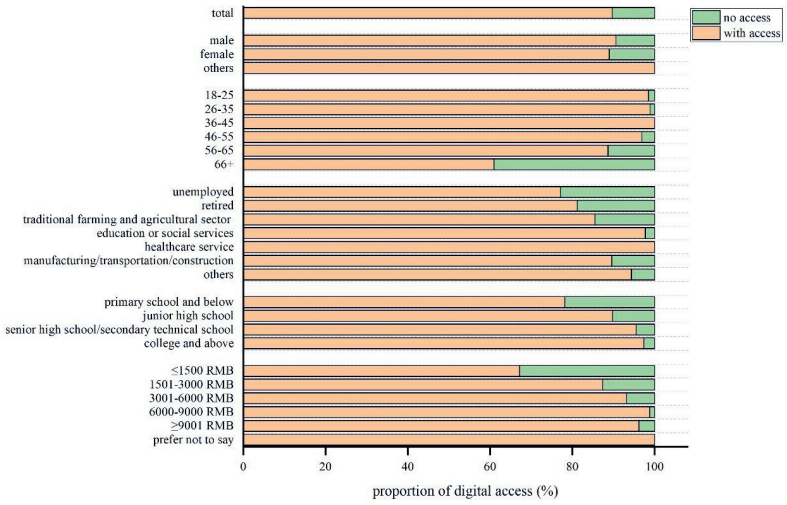


Figure 4 Proportion of people having digital access across different sociodemographic characteristics

Attitudes towards eHealth

Participants obtained an average score of 6.9 (SD 1.8, reference range: 2-10) in their attitudes towards eHealth, indicating a moderate level of positive attitude. As illustrated in Figure 5, the difference is not evident between males and females. Individuals aged 26-35, those working in healthcare or other occupations, and those with a college degree or higher tend to have more positive attitudes toward eHealth. Furthermore, a "U" pattern is noticed in income levels, wherein participants with both the lowest and

highest income levels exhibit more positive attitudes.

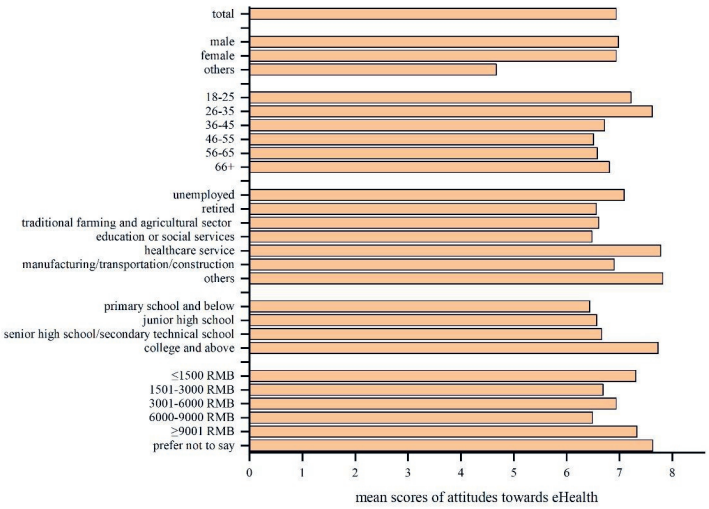


Figure 5 Mean scores of attitude towards eHealth

Prediction of eHealth literacy (RQ2)

417 cases were included in univariable and multivariable regression analyses. Univariable and multivariable linear regression results are presented in Table 2. Univariable analyses showed that younger age (b=-0.26, P<.001), working in health care service (b=8.07, P<.001) or others (b=2.77, P=.02), higher educational level (b=3.70, P<.001) and monthly income (b=2.75, P<.001), having digital access (b=14.08, P<.001), more frequent eHealth use (b=2.29, P<0.001) and a more positive attitude towards eHealth (b=1.09, P<.001) were significantly associated with higher eHL while being unemployed (b=-4.00, P=.009) or retired (b=-4.01, P=.009) was associated with lower eHL (Table 2). In the multivariable analysis, step 1 showed that participants with younger age, higher educational level and income were found to be significantly associated with higher eHL scores (P<.001) (Table 2). Occupation was no longer significant (P > .05). Controlling for these variables, Step 2 showed that having digital access (b=6.35, P<.001), more frequent eHealth use (b=1.14, P<.001) and a more positive attitude towards eHealth (b=0.47, P<.001) were associated with higher eHL scores (Table 2).

Table 2 Prediction for eHealth literacy (N=417)

Predictors	Categories	Univariable analysis			Multivariable analysis					
					Step 1			Step 2		
		b[a] (95% CI[b])	*β*[c]	*P* value	*b* (95% CI)	*β*	*P* value	*b* (95% CI)	*β*	*P* value
Gender	Male	1								
	Female	-0.31 (-1.91, 1.29)	-0.02	.70						
Age	Age in years	-0.26 (-0.29, -0.22)	-0.58	< .001	-0.14 (-0.18, -0.10)	-0.32	< .001	-0.10 (-0.13, -0.05)	-0.21	< .001
Occupation	Education or social services	1	1		1	1		1	1	
	Unemployed	-4.00 (-6.96, -1.01)	-0.13	.009	-0.86 (-3.25, 1.53)	-0.03	.48	0.04 (-2.12, 2.20)	0.00	.97
	Retired	-4.01 (-6.27, -1.76)	-1.95	.001	-0.73 (-2.65, 1.18)	-0.04	.45	0.61 (-2.33, 1.11)	-0.03	.48
	Traditional farming and agricultural sector	-2.00 (-4.37, 0.37)	-0.09	.10	0.58 (-1.31, 2.47)	0.03	.55	0.52 (-1.20, 2.23)	0.02	.55
	Healthcare service	8.07 (5.07, 11.08)	0.27	< .001	1.34 (-1.19, 3.87)	0.04	.30	1.52 (-0.78, 3.82)	0.05	.19
	Manufacturing/transportation/construction	-0.58 (-3.26, 2.09)	0.02	.67	0.07 (-2.05, 2.18)	0.00	.95	0.52 (-1.38, 2.42)	0.02	.59
	Others	2.77 (0.36, 5.19)	0.12	.02	1.03 (-0.94, 3.00)	0.05	.31	1.20 (-0.60, 2.99)	0.05	.19
Educational level	Educational level	3.70 (3.18, 4.23)	0.56	< .001	2.18 (1.61, 2.74)	0.33	< .001	2.02 (1.50, 2.54)	0.31	< .001
Income	Income	2.75 (2.17, 3.33)	0.41	< .001	1.45 (0.94, 1.96)	0.22	< .001	1.10 (0.64, 1.57)	0.17	< .001
CLD[d] knowledge	Knowledge scores	-0.03 (-0.24, 0.18)	-0.01	.79						
Digital access	No	1						1		
	Yes	14.08 (11.93, 16.23)	0.54	< .001				6.35 (4.35, 8.36)	0.24	< .001
eHealth use	Frequency	2.29 (1.65, 2.92)	0.33	< .001				1.14 (0.64, 1.63)	0.16	< .001
Attitude towards eHealth		1.09 (.66, 1.52)	0.24	< .001				0.47 (0.16, 0.77)	0.10	.003

a: unstandardized coefficient.

b: confidence interval.

c: standardized coefficient.

d: chronic lung disease.

Multivariable analysis step 1: R^2=0.49; step 2: R^2 =0.60.

Discussion

Principal findings

This study investigated eHealth literacy and its associated factors among the general population in China, with a specific focus on sociodemographic characteristics, CLD knowledge, digital access, eHealth use and attitude towards eHealth. Thereby it provides valuable insights, specifically for LMIC. We used both online and offline data collection and managed to include people with limited digital access and a lower SEP. In the first part of the study, we explored the eHL level, CLD knowledge, digital access and attitude towards eHealth across different sociodemographic groups. Overall, participants had relatively low levels of eHL and CLD knowledge, and had a moderate positive attitude towards eHealth. Higher eHL scores were noticed among younger participants, those working in healthcare service, and individuals with a higher educational degree or monthly income. While most participants had digital access, a large proportion of the elderly and those with a low SEP did not. In the second part of the study, univariable regression showed that all variables except gender and CLD knowledge were significantly associated with eHL. Multivariable regression analyses revealed that younger age, higher educational and income level, having digital access, more frequent eHealth use, and more positive attitude towards eHealth were uniquely associated with higher eHL. Occupation was no longer significant in the final model.

Comparison with prior work

Our findings revealed a relatively low eHL level with remarkable sociodemographic disparities among the general population in China. The eHL in our study is much lower compared with similar studies using the EHEALS in Hungary [55], Portugal [56] and Korea [57]. When zooming into LMICs, the scores found in our study are lower compared with EHEALS studies conducted on Pakistani university students [58], but similar to that among chronic patients in northwest Ethiopia [59] and primary care patients in Malaysia [60]. The eHL difference could be explained by the variations in ICT infrastructure such as ICT access, adoption and integration with healthcare, personal digital skills, policies and social support across these countries [61]. Despite the active policy to advance ICT, China still faces challenges in promoting nationwide ICT access, especially among the elderly and in underserved areas [21, 62]. These comparisons highlight the importance of considering regional and contextual factors, target population and sampling methods when interpreting eHL levels. In our study, obvious sociodemographic differences in eHL were noticed, especially across age,

education and income levels, which directs the further exploration for association analysis. Our finding that younger participants had higher eHL scores is in line with previous studies [8, 10]. This might be because young people grew up in a digital environment, therefore being more exposed to eHealth resources and more proficient in navigating and using them to access health information [63]. The middle-aged and elderly people, however, were less engaged in internet use, and even less likely to use it for searching health information [64]. Furthermore, people working in healthcare services in our study reported higher eHL compared to other sectors, possibly because these people are more equipped with health knowledge and have been exposed to a wide range of health information, with sufficient experience dealing with diseases and technologies. eHL of HCPs can also vary across ages, profession types, years of experience, access to internet and living areas, as reported by surveys among HCPs in Ethiopia [65] and Iran [66]. In our study, occupation was not found to be uniquely associated with eHL, as other variables could overshadow its effect. The positive association of higher educational degrees and income with higher eHL was also reported in previous studies conducted in China and Israel [10, 26]. This is probably because individuals with higher socioeconomic status have more access to digital resources, ensuring more familiarity with and use of digital technology [67].

After controlling for sociodemographic characteristics, our findings revealed that digital access, more frequent eHealth use and positive attitude towards eHealth were uniquely associated with higher eHL. Despite the majority of participants having digital access, a large proportion of the elderly and low SEP population reported no digital access in our study, consistent with findings from a national longitudinal study in China [68]. Previous eHL surveys rarely included digital access as a factor, typically focusing on internet users or using online recruitment methods, thus overlooking the existing digital divide. This divide hinders them from engaging in online healthcare services and exacerbates health inequities [69]. Of note, it is not a regional but a global issue caused by poverty, low literacy, and lack of interest or motivation to use technology [70], especially in disadvantaged populations, such as the low SEP population, racial or ethnic minorities, underserved rural populations, and sexual and gender minorities [20]. Zoe et al., in a study involving both online and offline recruitment methods, discovered that poor eHL was associated with a lack of access to mobile devices among breast cancer survivors in UK [71]. This suggests digital access provides more opportunities for self-directed learning content regarding health-related knowledge and skills, and enables more engagement in healthcare, and communication with HCPs, peers and

support networks, thereby enhancing people's eHL.

Our finding that more frequent eHealth use is associated with higher eHL is supported by a study showing a substantial positive association between higher eHL and more frequent use of health applications and internet to find health information among cardiac patients in Norway and Denmark [72]. In terms of attitude towards eHealth, we found participants generally exhibited positive attitudes, particularly among those with younger ages or higher educational levels, but no apparent pattern was found for income levels. This result is supported by other studies conducted in German HCPs and Saudi Arabian netizens [73, 74]. Despite the difference in measurement and target population, most of the participants they investigated either expected benefits of eHealth for a multitude of therapeutic areas or believed it saves time, labor and costs. By synthesizing existing evidence from both HIC and LMIC, a meta-analysis study [23] coincided with our finding that lower eHL is associated with a more negative attitude towards eHealth despite the different measurement tools of attitude. However, they did not compare the difference between HIC and LMIC, but between Asian countries and Middle Eastern countries instead, indicating geographic disparities in this correlation and underscoring the necessity of tailoring eHealth initiatives to specific regional contexts.

The generally low scores in CLD knowledge suggest a lack of understanding of CLD in our sample drawn from the general population. Similarly, a mixed-method study in China found that even CLD patients had limited knowledge regarding CLD causes and potential actions they could take [75]. In our study, a number of participants did not check any environmental factors as potential causes of CLD, implying there may be a lack of awareness about the role of environmental factors in the development of CLD. Similar results were found in the FRESHAIR study, such that fewer community members and HCP in LMIC perceived environmental factors, especially occupational and household air pollution, as CLD causes compared with behavioral factors such as smoking [48].

Implications and recommendations

Our findings highlight that targeted education and training programs should be developed to improve eHL and CLD knowledge among general populations in China. Such interventions prove to be an effective way to improve eHL when adequate methods are chosen, such as face-to-face teaching or web-based education, and when guided by a conceptual framework and sustained for a longer duration [76]. Approaches to improve CLD-specific knowledge include involving the community and relevant

stakeholders to identify the local context, and co-create educational materials in an easily-to-understand manner, such as using plain language and illustrations, which has been proven feasible and effective in LMICs [77]. Considering the sociodemographic differences in eHL and attitude towards eHealth, tailoring eHealth to different groups to meet their specific needs and preferences is necessary. The presence of the digital divide underscores the necessity for policy makers and technology developers to ensure universal access to digital technology and minimize the health disparity in disadvantaged populations. This requires concerted efforts at both individual levels such as improving digital skills, motivations, social support networks, and systemic levels by developing user-centered design, improving technology infrastructure and strengthening transdisciplinary collaboration [78].

Future eHL studies could employ offline recruitment to reach a more inclusive sample, as a large proportion of disadvantaged populations would be excluded by solely online recruitment due to inaccessibility to digital technology. Furthermore, while EHEALS is the most commonly used instrument to measure eHL [35], the absence of existing norms or benchmarks makes it difficult to assess and compare eHL levels in different populations and regions. Therefore, we strongly recommend that consultation and collaboration with multidisciplinary stakeholders should be engaged to gather inputs in the development of national or international norms, such as workshops, focus groups, or expert panels. This would provide a standardized framework when measuring eHL across different contexts and guide the local policymakers to set goals and implement eHealth interventions more effectively in the future. Additionally, a larger and representative sample can also be reached for further validation of the questionnaire or development of standardized tools in the future.

Limitations and strengths

Several limitations in this study should be noted. First, a causal conclusion cannot be reached due to the nature of a cross-sectional survey. Second, the conclusion should be extrapolated with caution because the sample is not representative. Third, there could be some potential response bias during the survey although investigators tried to mitigate this risk. Fourth, some questionnaire items were self-designed as there were no standardized and validated tools to evaluate digital access and attitude towards eHealth, which might influence the reliability and validity of our results. However, we optimized the validity of our questionnaire by identifying relevant constructs from literature and combining existing standardized tool EHEALS. Furthermore, we did not

take place of residence into consideration as some participants travel between rural and urban areas for work or study, making it difficult to explore rural-urban differences in eHL accurately.

Despite these limitations, our study also benefits from several strengths. The sociodemographic patterns provided adequate information for group disparities in eHL and facilitated further exploratory analyses. Our inclusive approach successfully engaged participants with a low SEP and limited digital access in China through both online and offline recruitment strategies, distinguishing our survey from others. Additionally, this study provided more insights into eHL and its associated factors, especially for LMICs, as we investigated the digital access and attitude towards eHealth, which were rarely explored in previous studies, inspiring future studies to explore their causality further.

Conclusion

This study contributes to our understanding of eHealth literacy and its associated factors in the general population in China. Our sample had a relatively low eHealth literacy and chronic lung disease knowledge level, but held a positive attitude towards eHealth based on our predefined ranges. Younger age, higher educational and income level, having digital access, more frequent eHealth use and more positive attitude towards eHealth were significantly and uniquely associated with higher eHealth literacy. Future research can develop targeted interventions to improve eHealth literacy and knowledge of chronic lung disease. Tailoring eHealth to different groups to meet their specific needs and preferences is necessary to improve people's attitudes towards eHealth. Multisectoral efforts should be made to promote digital access and narrow health inequalities arising from the digital divide, especially in the disadvantaged population. National and international norms should be formulated for evaluating and comparing eHealth literacy in different contexts.

Abbreviations

CI: confidence interval
CLD: chronic lung disease
COPD: chronic obstructive pulmonary disease
eHL: eHealth literacy
EHEALS: the eHealth literacy scale
FRESHAIR: Free Respiratory Evaluation and Smoke exposure reduction by primary Health cAre Integrated gRoups
GINA: the Global Initiative for Asthma
GOLD: the Global Initiative for COPD
HCP: healthcare professional
HIC: high income countries
LMIC: low- and middle- income countries
SEP: socioeconomic position
UTAUT: Unified Theory of Acceptance and Use of Technology

Appendixes

Appendix 1 Questionnaires

Survey study: using digital tools to find health information

Introduction:

Dear Sir/Madam,

Very glad to invite you to participate in our survey! We are researchers from Leiden University Medical Centre (LUMC) in The Netherlands and Wuhan University in China. We are conducting a survey to explore how people in China use digital tools to find health information to deal with health issues, how they feel about it, and what they know about chronic lung disease. Your opinions and experiences are very valuable to our study and will be beneficial to the further digital health intervention in chronic lung disease in our country.

There is no any health risk in the survey. The data collected in this questionnaire will be stored confidentially in LUMC until this study is published and used for research purposes only. You won't be identifiable in publications resulting from the study. This is completely voluntary and you can stop at any point. The research project is performed by LUMC in collaboration with Wuhan University, and has been reviewed by the Medical Ethics Committee of Wuhan University.

There is no right or wrong answer, you just need to check the "√" before the option according to your actual situation. The survey will take about 3 minutes, thank you for your support and cooperation!

If any questions or you want to get an update about the results of this survey, please don't hesitate to contact the project leader Mr. Sun by email 2020283050094@whu.edu.cn.

Did you read and understand the above and would you like to participate in this survey?

☐yes ☐no

Demographics

We first have some questions about your background.

1. Gender: ☐male ☐female ☐other
2. Age (in years): _____

3. Current occupation

☐Housewife/man ☐Unemployed ☐Retired (please also indicate your former occupational sector by ticking the appropriate box) ☐Traditional farming and agricultural sector ☐ Education or social services ☐Healthcare service ☐Manufacturing sector ☐ Transportation/construction ☐Others

4. Highest attained educational level

☐primary school and below ☐junior high school ☐senior high school/secondary technical school ☐college and above

5. Your personal monthly income (only yourself, NOT the household income)

☐≤1500 RMB ☐1501-3000 RMB ☐3001-6000 RMB ☐6001-9000 RMB ☐≥9001 RMB ☐prefer not to say

eHealth literacy

The following questions are about health resources on the Internet.

6. I know what health resources are **available** on the Internet.

☐strongly disagree ☐disagree ☐neutral ☐agree ☐strongly agree

7. I know **where to find** helpful health resources on the Internet.

☐strongly disagree ☐disagree ☐neutral ☐agree ☐strongly agree

8. I know **how to find** helpful health resources on the Internet.

☐strongly disagree ☐disagree ☐neutral ☐agree ☐strongly agree

9. I know how to use the Internet **to answer my questions** about health.

☐strongly disagree ☐disagree ☐neutral ☐agree ☐strongly agree

10. I know how to **use the health information** I find on the Internet to help me.

☐strongly disagree ☐disagree ☐neutral ☐agree ☐strongly agree

11. I have the **skills** I need to evaluate the health resources I find on the Internet.

☐strongly disagree ☐disagree ☐neutral ☐agree ☐strongly agree

12. I can **tell high quality** health resources from low quality health resources on the Internet.

☐strongly disagree ☐disagree ☐neutral ☐agree ☐strongly agree

13. I **feel confident** in using information from the Internet to make health decisions.

☐strongly disagree ☐disagree ☐neutral ☐agree ☐strongly agree

Story

Below is a story about a fictional person. Please read the story carefully and then answer the subsequent questions. We are interested in your own personal views of what you think about the story. There are no wrong or right answers.

Story: Xiulian is a mother living in a village. She is 35 years old and lives with her husband and her children. When her husband works, she takes care of the children. Since three years, she notices that she becomes ***breathless more easily than others of her age****. She especially feels breathless when she is walking up a hill. Also, she often feels* ***tired****. She has* ***a constant cough that produces sputum, especially in the mornings****. The breathlessness, fatigue and cough with sputum increase over time. Occasionally there are periods, in which breathing becomes extremely difficult. Usually such a period starts with a cold. Once she had tried antibiotics in such a severe period, but that did not seem to help. These periods usually last for a week, and then the situation improves until she feels almost the same again as before the period.*

14. Do you have the same condition like Xiulian?
□yes □no

15. Does anyone close to you have the same condition like Xiulian?

□yes □no

16. We are interested in what you consider possible causes of this disease. What led to Xiulian' disease in your opinion?

Possible causes	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
Stress or worry	☐	☐	☐	☐	☐
It runs in the family	☐	☐	☐	☐	☐
A germ or virus	☐	☐	☐	☐	☐

Kitchen smoke	☐	☐	☐	☐	☐
Diet or eating habits	☐	☐	☐	☐	☐
Chance or bad luck	☐	☐	☐	☐	☐
Poor medical care in the past	☐	☐	☐	☐	☐
Pollution in the environment	☐	☐	☐	☐	☐
Family problems or worries	☐	☐	☐	☐	☐
Overwork	☐	☐	☐	☐	☐
Ageing	☐	☐	☐	☐	☐
Dust	☐	☐	☐	☐	☐
Alcohol	☐	☐	☐	☐	☐
Smoking	☐	☐	☐	☐	☐
Second hand smoke	☐	☐	☐	☐	☐
Witchcraft	☐	☐	☐	☐	☐
The weather	☐	☐	☐	☐	☐
Spirits	☐	☐	☐	☐	☐
Brought from other regions	☐	☐	☐	☐	☐
An allergy	☐	☐	☐	☐	☐
Lung infection or tuberculosis in the past	☐	☐	☐	☐	☐
Occupational pollution	☐	☐	☐	☐	☐
Smoke exposure of mother during pregnancy	☐	☐	☐	☐	☐
Exercise	☐	☐	☐	☐	☐

Digital access

17. Do you have the access to digital technology (e.g. cellphone, computer, laptop)?

☐yes ☐no (If no, skip to **question 24**)

18. Do you get an internet connection with your digital technology?

☐yes ☐no (If no, skip to **question 24**)

19. Do you use your digital technology to get health information?

☐yes ☐no (If no, skip to **question 24)**

20. What kind of source do you usually use to get health information? **(multiple choice)**

☐Search engine (e.g. Baidu) ☐Social media platforms (e.g. Wechat/Ticktock/Weibo) ☐ Online video platforms (e.g. Youku/Souhu/Tencent Video) ☐Health websites (e.g. Haodf.com, Guahao.com) ☐Health applications (e.g. Dingxiang Doctor/Ali Health) ☐ Online communities and forums (e.g. Baidu Tieba/Zhihu) ☐Telemedicine Services (e.g. Chunyu Doctor/Ping An Good Doctor)

21. How often do you use them?

☐hardly never (less than once a week) (If never, skip to **question 24**)

☐rarely (once a week)

☐sometimes (2-3 times a week)

☐often (4-5 times a week)

☐daily (≥6 times a week)

Attitudes towards eHealth

The following questions are about your opinion on eHealth applications or platforms. Please answer the following questions according to the above source you use most often.

22. I consider it to be easy to use.

☐strongly disagree ☐disagree ☐neutral ☐agree ☐strongly agree

23. I believe it can provide valuable health information and support.

☐strongly disagree ☐disagree ☐neutral ☐agree ☐strongly agree

The following part is **ONLY** for people who **have no access** to eHealth.

24. I expect it to be easy to use.

☐strongly disagree ☐disagree ☐neutral ☐agree ☐strongly agree

25. I expect it to provide valuable health information and support.

☐strongly disagree ☐disagree ☐neutral ☐agree ☐strongly agree

This is the end of the survey. Thank you very much for taking the time to complete the survey, and for sharing your experiences with us!

Name investigator: Date:

Questionnaire Translation (Chinese)

问卷调查：使用数字工具查询健康信息

尊敬的先生/女士：

很高兴邀请您参加我们的调查！我们是来自荷兰莱顿大学医学中心（LUMC）和中国武汉大学的研究人员，我们正在开展一项调查，以了解中国当下的人们如何使用数字技术查找健康信息来处理健康问题，对数字技术的感受，以及对慢性肺病的了解程度。您的观点和经验对我们的研究非常有价值，有助于我国进一步开展慢性肺病的数字健康干预。

本调查不存在任何健康风险，收集的数据将保密储存于 LUMC 且仅用于研究目的，直到本研究发表，您的身份信息也不会出现在调查中。调查纯属自愿，您可以随时终止。该项目由 LUMC 与武汉大学合作开展，并已通过武汉大学医学伦理委员会的审查。该调查没有正确或错误的答案，只需根据您的实际情况勾选选项前的“√”。本次调查耗时约 3-8 分钟，感谢您的支持与配合!

如果有任何问题或您想获得有关调查结果的最新信息，请通过电子邮件 2020283050094@whu.edu.cn 与项目负责人孙先生联系。

您是否阅读和知晓以上内容，并愿意参与本次调查?
☐是☐否

人口统计资料

首先我们想了解一些您的背景信息。

1. 性别：☐男 ☐女 ☐其他

2. 年龄：☐☐岁

3. 职业：

☐家庭主妇/煮夫 ☐失业 ☐退休**（如已退休，请在后面的方格内加上您以前的职业）**
☐传统养殖业/农业 ☐教育或社会服务 ☐医疗保健服务 ☐制造业 ☐交通运输/建筑
☐其他

4. 最高学历

□小学及以下 □初中 □高中/中专 □大专及以上

5. 您的个人月收入

□≤1500 元 □1501-3000 元 □3001-6000 元 □6001-9000 元 □≥9001 元 □不便透露

电子健康素养

以下问题是关于网络健康资讯的内容。

6. 我知道什么样的健康资讯是**可以从互联网上找到**的。
□强烈不同意 □不同意 □中立 □同意 □强烈同意

7. 我知道网上可以**从何处找到**有用的健康资讯。

□强烈不同意 □不同意 □中立 □同意 □强烈同意

8. 我知道**怎样在互联网上找到**有用的资讯。

□强烈不同意 □不同意 □中立 □同意 □强烈同意

9. 我知道如何利用互联网去**寻找我想知道的健康问题的答案**。

□强烈不同意 □不同意 □中立 □同意 □强烈同意

10. 我知道如何利用我在互联网上找到的健康资讯去**解决问题**。

□强烈不同意 □不同意 □中立 □同意 □强烈同意

11. 我**掌握必要的技能**可以让我评估互联网上找到的资讯是否有用。

□强烈不同意 □不同意 □中立 □同意 □强烈同意

12. 我可以**区分互联网上健康资讯质量**的高低。

□强烈不同意 □不同意 □中立 □同意 □强烈同意

13. 我可以**自信地使用互联网**上找到的资讯去做出有关健康的决定

□强烈不同意 □不同意 □中立 □同意 □强烈同意

疾病知识

以下是一个虚构故事，请仔细阅读然后回答下面的问题。我们对您的看法很感兴趣，以下没有正确或错误的答案。

*故事:秀莲是一位住在农村的母亲，今年 35 岁，与丈夫和孩子住在一起,丈夫工作时，她照顾孩子。三年来，她发现自己比同龄人更容易**上气不接下气，爬坡时更加喘不过气来**。此外，她经常感到累，不停地**咳嗽、咳痰，尤其是早晨**。随着时间的推移，呼吸困难，疲劳和咳嗽带痰加重。偶尔有一段时间，呼吸变得极其困难。通常这种时期始于感冒。她曾经在严重时尝试过抗生素，但似乎没有奏效。这种症状通常持续一周，然后情况好转，直到她感觉和发病前几乎一样。*

14. 您有像秀莲这样的症状吗?

□是 □否

15. 您身边人有秀莲这样的症状吗？

□是 □否

16. 我们想了解您对该病病因的看法，您认为导致秀莲患病的可能原因有哪些？

可能的病因	强烈不同意	不同意	中立	同意	强烈同意
压力或担忧	□	□	□	□	□
家族遗传	□	□	□	□	□
细菌或病毒	□	□	□	□	□
厨房烟尘	□	□	□	□	□
饮食或饮食习惯	□	□	□	□	□
偶然或者厄运	□	□	□	□	□
过去的医疗服务不好	□	□	□	□	□
环境污染	□	□	□	□	□
家庭问题或忧虑	□	□	□	□	□
过劳	□	□	□	□	□
衰老	□	□	□	□	□
粉尘	□	□	□	□	□
酒精	□	□	□	□	□
吸烟	□	□	□	□	□

二手烟	☐	☐	☐	☐	☐
巫术	☐	☐	☐	☐	☐
天气	☐	☐	☐	☐	☐
鬼魂	☐	☐	☐	☐	☐
从其他地区带来	☐	☐	☐	☐	☐
过敏	☐	☐	☐	☐	☐
曾有肺部感染或结核	☐	☐	☐	☐	☐
职业污染	☐	☐	☐	☐	☐
母亲怀孕期间吸烟暴露	☐	☐	☐	☐	☐
锻炼	☐	☐	☐	☐	☐

电子健康可及性

17. 你是否有机会使用电子设备(如手机、电脑、平板)获取健康信息?

☐是 ☐否 （如果否，跳到 **24 题**）

18. 你的电子设备有联网吗?

☐是☐否 （如果否，跳到 **24 题**）

19. 您是否使用电子设备查询健康信息？

☐是☐否 （如果否，跳到 **24 题**）

20. 您通常使用以下哪种平台来源来获取健康信息?(多选)

☐搜索引擎（如：百度） ☐社交媒体平台（微信/抖音/微博） ☐在线视频平台（优酷/搜狐/腾讯视频） ☐健康网站（Haodf.com, Guahao.com）☐健康应用（丁香医生/阿里健康） ☐线上社区和论坛（贴吧/知乎） ☐远程医疗服务（春雨医生/平安好医生）

21. 您使用这些电子健康应用程序或平台的频率如何?

☐几乎不(每周少于 1 次) 如果是，跳到 **24 题**）

☐很少(每周 1 次)

☐有时(每周 2-3 次)

☐经常(每周 4-5 次)

□每天(每周≥6 次)

对电子健康的态度

以下内容是关于您对电子健康应用和平台的看法，请根据您最常用的应用或平台作答。

22. 我认为它很容易使用。

□强烈不同意 □不同意 □中立 □同意 □强烈同意

23. 我相信它可以提供有价值的健康信息和支持。

□强烈不同意 □不同意 □中立 □同意 □强烈同意

以下部分仅由**没有电子设备**的人作答。

24. 我希望它很容易使用。

□强烈不同意□不同意□中立□同意□强烈同意

25. 我希望它可以提供有价值的健康信息和支持。

□强烈不同意□不同意□中立□同意□强烈同意

调查结束，非常感谢您抽出时间完成调查并与我们分享您的经历！

调查员姓名： 日期：

References

1. Norman CD, Skinner HA. eHealth Literacy: Essential Skills for Consumer Health in a Networked World. J Med Internet Res. 2006;8(2):e9.
2. Hsu W, Chiang C, Yang S. The effect of individual factors on health behaviors among college students: the mediating effects of eHealth literacy. J Med Internet Res. 2014;16(12):e287.
3. Tennant B, Stellefson M, Dodd V, Chaney B, Chaney D, Paige S, et al. eHealth literacy and Web 2.0 health information seeking behaviors among baby boomers and older adults. J Med Internet Res. 2015;17(3):e70.
4. Lin CY, Ganji M, Griffiths MD, Bravell ME, Brostrom A, Pakpour AH. Mediated effects of insomnia, psychological distress and medication adherence in the association of eHealth literacy and cardiac events among Iranian older patients with heart failure: a longitudinal study. Eur J Cardiovasc Nurs. 2020;19(2):155-64.
5. Swire-Thompson B, Lazer D. Public Health and Online Misinformation: Challenges and Recommendations. Annu Rev Public Health. 2020;41:433-51.
6. Huang CL, Chiang CH, Yang SC. eHealth Literacy and Beliefs About Medicines Among Taiwanese College Students: Cross-sectional Study. JMIR medical informatics. 2021;9(11):e24144.
7. Do BN, Tran TV, Phan DT, Nguyen HC, Nguyen TTP, Nguyen HC, et al. Health Literacy, eHealth Literacy, Adherence to Infection Prevention and Control Procedures, Lifestyle Changes, and Suspected COVID-19 Symptoms Among Health Care Workers During Lockdown: Online Survey. J Med Internet Res. 2020;22(11):e22894.
8. Park SY, Chung S. E-health literacy and associated factors among Korean adults during the COVID-19 pandemic: age-group differences. Health Promot Int. 2023;38(5).
9. Zhang L, Chung S, Shi W, Candelaria D, Gallagher R. Online Health Information-Seeking Behaviours and eHealth Literacy among First-Generation Chinese Immigrants. Int J Environ Res Public Health. 2023;20(4).
10. Guo Z, Zhao SZ, Guo N, Wu Y, Weng X, Wong JY, et al. Socioeconomic Disparities in eHealth Literacy and Preventive Behaviors During the COVID-19 Pandemic in Hong Kong: Cross-sectional Study. J Med Internet Res. 2021;23(4):e24577.
11. Valizadeh-Haghi S, Rahmatizadeh S. eHealth Literacy and General Interest in Using Online Health Information: A Survey Among Patients with Dental Diseases. Online J Public Health Inform. 2018;10(3):e219.
12. Kristjansdottir O, Welander Tarneberg A, Stenstrom P, Castor C, Kristensson Hallstrom I. eHealth literacy and socioeconomic and demographic characteristics of parents of children needing paediatric surgery in Sweden. Nurs Open. 2023;10(2):509-24.
13. Tesfa GA, Yehualashet DE, Ewune HA, Zemeskel AG, Kalayou MH, Seboka BT. eHealth Literacy and its Associated Factors Among Health Professionals During the COVID-19 Pandemic in Resource-Limited Settings: Cross-sectional Study. JMIR formative research. 2022;6(7):e36206.
14. Maroney K, Curtis LM, Opsasnick L, Smith KD, Eifler MR, Moore A, et al. eHealth

literacy and web-based patient portal usage among kidney and liver transplant recipients. Clin Transplant. 2021;35(2):e14184.
15. Knitza J, Simon D, Lambrecht A, Raab C, Tascilar K, Hagen M, et al. Mobile Health Usage, Preferences, Barriers, and eHealth Literacy in Rheumatology: Patient Survey Study. JMIR Mhealth Uhealth. 2020;8(8):e19661.
16. Sinan O, Ayaz-Alkaya S, Akca A. Predictors of eHealth literacy levels among nursing students: A descriptive and correlational study. Nurse Educ Pract. 2023;68:103592.
17. Sozeri Ozturk E, Canbolat O, Polat U. Internet Use, eHealth Literacy, and Influencing Factors in Turkish Cancer Patients: A Descriptive and Correlational Study. Semin Oncol Nurs. 2023;39(4):151469.
18. Reddy H, Joshi S, Joshi A, Wagh V. A Critical Review of Global Digital Divide and the Role of Technology in Healthcare. Cureus. 2022;14(9):e29739.
19. Ernsting C, Dombrowski SU, Oedekoven M, JL OS, Kanzler M, Kuhlmey A, et al. Using Smartphones and Health Apps to Change and Manage Health Behaviors: A Population-Based Survey. J Med Internet Res. 2017;19(4):e101.
20. Adedinsewo D, Eberly L, Sokumbi O, Rodriguez JA, Patten CA, Brewer LC. Health Disparities, Clinical Trials, and the Digital Divide. Mayo Clin Proc. 2023;98(12):1875-87.
21. Hong YA, Zhou Z, Fang Y, Shi L. The Digital Divide and Health Disparities in China: Evidence From a National Survey and Policy Implications. J Med Internet Res. 2017;19(9):e317.
22. Fong MWL. Digital divide: The case of developing countries. Issues in Informing Science and Information Technology. 2009;6(2):471-8.
23. Elgamal R. Meta-analysis: eHealth literacy and attitudes towards internet/computer technology. Patient Educ Couns. 2024;123:108196.
24. Frishammar J, Essén A, Bergström F, Ekman T. Digital health platforms for the elderly? Key adoption and usage barriers and ways to address them. Technological Forecasting and Social Change. 2023;189.
25. Center CINI. The 52nd Statistical Report on China's Internet Development. China Internet Network Information Center; 2023 08.2023.
26. Green G. Seniors' eHealth literacy, health and education status and personal health knowledge. Digit Health. 2022;8:20552076221089803.
27. Arcury TA, Sandberg JC, Melius KP, Quandt SA, Leng X, Latulipe C, et al. Older Adult Internet Use and eHealth Literacy. J Appl Gerontol. 2020;39(2):141-50.
28. Yuan N, Lv ZH, Wen YY, Sun CR, Tao TY, Qian D. The relationship between eHealth literacy and palliative care knowledge, attitudes, and practice among nurses: a cross-sectional study. BMC nursing. 2023;22(1):76.
29. Hattab Y, Alhassan S, Balaan M, Lega M, Singh AC. Chronic Obstructive Pulmonary Disease. Crit Care Nurs Q. 2016;39(2):124-30.
30. Collaborators GBDCRD. Prevalence and attributable health burden of chronic respiratory diseases, 1990-2017: a systematic analysis for the Global Burden of Disease Study 2017. The Lancet Respiratory medicine. 2020;8(6):585-96.

31. Hall M. Chronic obstructive pulmonary disease and asthma. Home Healthc Nurse. 2012;30(10):603-12; quiz 12-4.
32. Fang L, Gao P, Bao H, Tang X, Wang B, Feng Y, et al. Chronic obstructive pulmonary disease in China: a nationwide prevalence study. The Lancet Respiratory medicine. 2018;6(6):421-30.
33. Zhang J, Zhou JB, Lin XF, Wang Q, Bai CX, Hong QY. Prevalence of undiagnosed and undertreated chronic obstructive pulmonary disease in lung cancer population. Respirology. 2013;18(2):297-302.
34. Gomes RE, Saraiva I, Morais-Almeida M. Awareness and education in lung diseases: Are we reaching the target? Pulmonology. 2022;28(5):330-2.
35. Lee J, Lee EH, Chae D. eHealth Literacy Instruments: Systematic Review of Measurement Properties. J Med Internet Res. 2021;23(11):e30644.
36. Crocker B, Feng O, Duncan LR. Performance-Based Measurement of eHealth Literacy: Systematic Scoping Review. J Med Internet Res. 2023;25:e44602.
37. Lwin MO, Panchapakesan C, Sheldenkar A, Calvert GA, Lim LKS, Lu J. Determinants of eHealth Literacy among Adults in China. J Health Commun. 2020;25(5):385-93.
38. Yang BX, Xia L, Huang R, Chen P, Luo D, Liu Q, et al. Relationship between eHealth literacy and psychological status during COVID-19 pandemic: A survey of Chinese residents. J Nurs Manag. 2021;29(4):805-12.
39. Xu RH, Bao XL, Shi LS, Wang D. Associations between eHealth literacy, mental health-seeking attitude, and mental wellbeing among young electronic media users in China during the COVID-19 pandemic. Frontiers in public health. 2023;11:1139786.
40. Zhao BY, Huang L, Cheng X, Chen TT, Li SJ, Wang XJ, et al. Digital health literacy and associated factors among internet users from China: a cross-sectional study. BMC Public Health. 2024;24(1):908.
41. Stellefson M, Paige SR, Alber JM, Chaney BH, Chaney D, Apperson A, et al. Association Between Health Literacy, Electronic Health Literacy, Disease-Specific Knowledge, and Health-Related Quality of Life Among Adults With Chronic Obstructive Pulmonary Disease: Cross-Sectional Study. J Med Internet Res. 2019;21(6):e12165.
42. Li S, Cui G, Kaminga AC, Cheng S, Xu H. Associations Between Health Literacy, eHealth Literacy, and COVID-19-Related Health Behaviors Among Chinese College Students: Cross-sectional Online Study. J Med Internet Res. 2021;23(5):e25600.
43. Wang Y, Song Y, Zhu Y, Ji H, Wang A. Association of eHealth Literacy with Health Promotion Behaviors of Community-Dwelling Older People: The Chain Mediating Role of Self-Efficacy and Self-Care Ability. Int J Environ Res Public Health. 2022;19(10).
44. Wang K, Gao X, Sun F, Bishop NJ. eHealth Literacy and Caregiver Burden Among Chinese Caregivers of Older Adults With Cognitive Impairment: Does Education Matter? J Appl Gerontol. 2021;40(12):1837-45.
45. Field A. Discovering statistics using SPSS. 3rd ed. London: SAGE Publications Ltd; 2009.
46. Wenjuanxing. https://www.wjx.cn/. Accessed.
47. Norman CD, Skinner HA. eHEALS: The eHealth Literacy Scale. J Med Internet Res.

2006;8(4):e27.
48. Brakema EA, van der Kleij R, Poot CC, An PL, Anastasaki M, Crone MR, et al. Mapping low-resource contexts to prepare for lung health interventions in four countries (FRESH AIR): a mixed-method study. Lancet Glob Health. 2022;10(1):e63-e76.
49. Xu RH, Zhou L, Lu SY, Wong EL, Chang J, Wang D. Psychometric Validation and Cultural Adaptation of the Simplified Chinese eHealth Literacy Scale: Cross-Sectional Study. J Med Internet Res. 2020;22(12):e18613.
50. Brakema EA, van der Kleij RM, Poot CC, Chavannes NH, Tsiligianni I, Walusimbi S, et al. A systematic approach to context-mapping to prepare for health interventions: development and validation of the SETTING-tool in four countries. BMJ Glob Health. 2021;6(1).
51. Global Initiative for Chronic Obstructive Lung Disease. https://goldcopd.org/. Accessed 06 December 2023.
52. Global Initiative for Asthma. https://ginasthma.org/. Accessed 06 December 2023 2023.
53. Ammenwerth E. Technology Acceptance Models in Health Informatics: TAM and UTAUT. Stud Health Technol Inform. 2019;263:64-71.
54. Gliem JA, Gliem RR, editors. Calculating, interpreting, and reporting Cronbach's alpha reliability coefficient for Likert-type scales. Midwest research-to-practice conference in adult, continuing, and community education; 2003: Columbus, OH.
55. Zrubka Z, Brito Fernandes O, Baji P, Hajdu O, Kovacs L, Kringos D, et al. Exploring eHealth Literacy and Patient-Reported Experiences With Outpatient Care in the Hungarian General Adult Population: Cross-Sectional Study. J Med Internet Res. 2020;22(8):e19013.
56. Almeida S, Pinto E, Correia M, Veiga N, Almeida A. Evaluating E-Health Literacy, Knowledge, Attitude, and Health Online Information in Portuguese University Students: A Cross-Sectional Study. Int J Environ Res Public Health. 2024;21(3).
57. Lee JJ, Poon CY, O'Connor S, Wong JYH, Kwok JYY, Choi EPH, et al. Associations of eHealth literacy and knowledge with preventive behaviours and psychological distress during the COVID-19 pandemic: a population-based online survey. BMJ Open. 2023;13(12):e069514.
58. Tariq A, Khan SR, Basharat A. Internet Use, eHealth Literacy, and Dietary Supplement Use Among Young Adults in Pakistan: Cross-Sectional Study. J Med Internet Res. 2020;22(6):e17014.
59. Shiferaw KB, Tilahun BC, Endehabtu BF, Gullslett MK, Mengiste SA. E-health literacy and associated factors among chronic patients in a low-income country: a cross-sectional survey. BMC Med Inform Decis Mak. 2020;20(1):181.
60. Wong SS, Lim HM, Chin AJZ, Chang FWS, Yip KC, Teo CH, et al. eHealth literacy of patients attending a primary care clinic in Malaysia and its associated factors: A cross-sectional study. Digit Health. 2022;8:20552076221135392.
61. Lythreatis S, Singh SK, El-Kassar A-N. The digital divide: A review and future research agenda. Technological Forecasting and Social Change. 2022;175.
62. Wang D, Zhou T, Wang M. Information and communication technology (ICT), digital divide and urbanization: Evidence from Chinese cities. Technology in Society. 2021;64.
63. Stellefson M, Hanik B, Chaney B, Chaney D, Tennant B, Chavarria EA. eHealth literacy

among college students: a systematic review with implications for eHealth education. J Med Internet Res. 2011;13(4):e102.
64. Sun X, Yan W, Zhou H, Wang Z, Zhang X, Huang S, et al. Internet use and need for digital health technology among the elderly: a cross-sectional survey in China. BMC Public Health. 2020;20(1):1386.
65. Shiferaw KB, Mehari EA. Internet use and eHealth literacy among health-care professionals in a resource limited setting: a cross-sectional survey. Adv Med Educ Pract. 2019;10:563-70.
66. Rangraz Jeddi F, Nabovati E, Mobayen M, Akbari H, Feizkhah A, Osuji J, et al. Health care needs, eHealth literacy, use of mobile phone functionalities, and intention to use it for self-management purposes by informal caregivers of children with burns: a survey study. BMC Med Inform Decis Mak. 2023;23(1):236.
67. Estrela M, Semedo G, Roque F, Ferreira PL, Herdeiro MT. Sociodemographic determinants of digital health literacy: A systematic review and meta-analysis. Int J Med Inform. 2023;177:105124.
68. Choi NG, Dinitto DM. The digital divide among low-income homebound older adults: Internet use patterns, eHealth literacy, and attitudes toward computer/Internet use. J Med Internet Res. 2013;15(5):e93.
69. Shaw RJ. Access to Technology and Digital Literacy as Determinants of Health and Health Care. Creat Nurs. 2023;29(3):258-63.
70. Saeed SA, Masters RM. Disparities in Health Care and the Digital Divide. Curr Psychiatry Rep. 2021;23(9):61.
71. Moon Z, Zuchowski M, Moss-Morris R, Hunter MS, Norton S, Hughes LD. Disparities in access to mobile devices and e-health literacy among breast cancer survivors. Support Care Cancer. 2022;30(1):117-26.
72. Ramstad KJ, Brors G, Pettersen TR, Deaton C, Palm P, Rotevatn S, et al. eHealth technology use and eHealth literacy after percutaneous coronary intervention. Eur J Cardiovasc Nurs. 2023;22(5):472-81.
73. Surmann M, Bock EM, Krey E, Burmeister K, Arolt V, Lencer R. [Attitudes towards using eHealth in psychiatry and psychotherapy : A pilot survey at the DGPPN Congress 2014]. Nervenarzt. 2017;88(9):1036-43.
74. Alajwari HA, Alfayez A, Alsalman D, Alanezi F, Alhodaib H, Al-Rayes S, et al. Knowledge and attitude of Saudi Arabian citizens towards telemedicine during the COVID-19 pandemic. Int Health. 2022;14(6):604-9.
75. Song X, Hallensleben C, Li B, Zhang W, Jiang Z, Shen H, et al. Illness Perceptions and Self-Management among People with Chronic Lung Disease and Healthcare Professionals: A Mixed-Method Study Identifying the Local Context. Healthcare (Basel, Switzerland). 2022;10(9).
76. Dong Q, Liu T, Liu R, Yang H, Liu C. Effectiveness of Digital Health Literacy Interventions in Older Adults: Single-Arm Meta-Analysis. J Med Internet Res. 2023;25:e48166.
77. Brakema EA, van Gemert FA, Williams S, Sooronbaev T, Emilov B, Mademilov M, et al.

Implementing a context-driven awareness programme addressing household air pollution and tobacco: a FRESH AIR study. NPJ primary care respiratory medicine. 2020;30(1):42.
78. Coetzer JA, Loukili I, Goedhart NS, Ket JCF, Schuitmaker-Warnaar TJ, Zuiderent-Jerak T, et al. The potential and paradoxes of eHealth research for digitally marginalised groups: A qualitative meta-review. Soc Sci Med. 2024;350:116895.

Chapter 5

Digital Health Education for Chronic Lung Disease: Scoping Review

Chao Sun, Huohuo Dai, Rianne M.J.J. van der Kleij, Rong Li, Hengchang Wu, Cynthia Hallensleben, Sofie H Willems, Niels H Chavannes

Journal of Medical Internet Research (2025). doi: 10.2196/53142

Chapter 5

Abstract

Background: Chronic lung disease (CLD) is one of the most prevalent noncommunicable diseases globally, significantly burdening patients and increasing health care expenditures. Digital health education (DHE) is increasingly important in chronic disease prevention and management. However, DHE characteristics and impacts in CLD are rarely reported.

Objective: This study aimed to provide an overview of the existing literature on DHE for CLD, with a focus on exploring the DHE mediums, content, mechanisms, and reported outcomes in CLD patients.

Methods: We searched PubMed, Web of Science, Embase, PsycINFO, and The Cochrane Library with the assistance of a librarian specialist. Articles were screened by the reviewer team with ASReview and Endnote X9 based on predefined inclusion and exclusion criteria and the PRISMA-ScR checklist. Quality assessment was conducted with the Critical Appraisal Skills Program tool. A descriptive analysis was used to summarize the study characteristics, DHE characteristics and outcomes.

Results: A total of 22 studies were included in this review with medium or high quality. They were published between 2000 and 2022, showing an increasing publication trend with year, mostly in developed countries (16/22, 73%). Websites and mobile applications (10/22, 45%) were the most widely used DHE medium. Education on self-management skills of CLD was the primary topic (21/22, 95%), 4/22 (18%) of which mentioned DHE mechanisms. Majority of studies reported positive changes in CLD awareness (14/16, 88%), clinical outcomes (3/6, 50%), DHE feasibility, acceptability, and satisfaction (6/8, 75%), lifestyle outcomes (3/3, 100%), and psychosocial outcomes (7/8, 88%). Only 2 studies reported cost-effectiveness (2/22, 9%).

Conclusions: Despite the heterogeneity of the study situation, some aspects can be concluded. Digital health education can improve disease awareness and clinical outcomes in patients with chronic lung disease, with good feasibility, acceptability and satisfaction through different mediums and learning content. There is still relatively little research among people in low- and middle-income countries. Future research should consider the impact on cost-effectiveness, duration, frequency and theoretical mechanism of the DHE to maximize the potential impact. It should also be conducted in the context of health services research to better reflect the real world.

Introduction

Chronic lung disease (CLD) is one of the most prevalent noncommunicable diseases globally, placing a large burden on patients and increasing health care expenditures, primarily including chronic obstructive pulmonary disease (COPD) and asthma. The total number of deaths due to CLD increased by 18% during the past three decades, with the highest mortality and disability-adjusted life years in regions with a low sociodemographic index, mainly in Africa, Middle East, Central Asia, Southeast Asia and South America, also namely low- and middle-income countries (LMIC) [1-3]. Smoking, air pollution and occupational exposure were the most significant risk factors for CLD [4]. Considering the acute exacerbations [5], complicated comorbidities and increasing costs of CLD [6], raising disease awareness and promoting healthy lifestyles through health education and management is crucial to improve people's health conditions among CLD patients and the general population.

Digital health education (DHE) offers knowledge or skills about health and health care in a timely and cost-effective manner by using all kinds of information and communication technologies (computer-assisted learning, mobile learning, and digital simulation-based learning), which is increasingly important in disease prevention and management [7]. With the accessibility of the internet and the popularity of advanced electronic or digital technology, diverse DHE mediums emerge, such as websites, multimedia, and mobile applications, providing learners with health information and instant feedback [8-11]. In addition, many studies reported a potential positive impact of digital health interventions on various diseases and mental health status, including improving people's knowledge, skills, adherence and other health-related outcomes [12-15]. However, despite the benefits of digital health intervention, the evidence is scarce regarding the characteristics and impact of DHE, especially in CLD patients.

Currently, suboptimal disease control in CLD patients is noticed due to their lower medication adherence and incorrect use of inhaler devices, which further contribute to increased exacerbation and hospitalizations [16]. This highlights the importance of DHE to deliver continuous and efficient educational content that helps them better understand their condition and treatment regardless of time and space. However, to the best of our knowledge, no reviews have focused on the characteristics and impact of DHE on CLD. It is essential to conduct a review to understand what aspects of DHE have been explored that could facilitate or hinder their adherence. Furthermore, previous studies on digital health interventions in CLD focused on multidimensional

interventions combining disease education with monitoring, coaching, and self-management (SM) [17-19]. A review is needed to know if DHE could also lead to significant changes, making a rationale for not giving all patients a multidimensional and, thereby, costly intervention.

Therefore, for this study, we aim to review the existing literature on DHE for CLD, with a focus on exploring the DHE mediums, content, mechanisms, and reported outcomes in CLD patients. Specifically, we intend to address the following research questions: (1) What are the reported characteristics of the DHE for CLD patients, in terms of type of DHE mediums, content, duration, frequency, and mechanisms? (2) What outcomes are reported in terms of impact of DHE on patients' knowledge of CLD, treatment, management and health-related outcomes? And (3) What is known about the feasibility, acceptability, and patient satisfaction of DHE for CLD patients?

Methods

Study Selection

Search strategies were developed with a medical information specialist from Leiden University Medical Center. Searches were conducted in PubMed, Web of Science, Embase, PsycINFO and The Cochrane Library combining key search terms "chronic lung disease," "digital technology," "health education," and related terms. To ensure a comprehensive scope by covering all relevant studies on DHE for CLD and capture a full breadth of the topic, studies were searched from inception to the day we conducted the search (February 26, 2023) without starting time limits. The complete search strategy is available in Multimedia Appendix 1. Literature screening was performed with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) [20] checklist (Multimedia Appendix 2). Inclusion and exclusion were performed according to the Participants, Intervention, Comparator, and Outcomes (PICO) strategy [21], shown in Textbox 1.

Textbox 1 Inclusion and exclusion criteria

Inclusion

- Participants: people diagnosed with CLD by a clinical professional.
- Intervention: digital health education focused on CLD (providing knowledge or skills about health and healthcare by using information and communication technologies).
- Comparison: no restriction.
- Outcome: all outcomes.
- Study design: randomized or nonrandomized controlled trials, qualitative and quantitative studies, mixed-methods studies, observational studies.

Exclusion

- Not DHE intervention or blended intervention (eg, interventions that combine education and skills training) that include less than 50% DHE.
- Studies with subjects <18 years of age.
- Commentaries, reviews, letters, dissertations, editorials, conference proceedings, books, and protocols.
- Not published in English.
- No full text available.
- Not peer-reviewed articles.

Justification

- To ensure a comprehensive review, different study designs were considered: qualitative studies can be used for exploring patients' experiences, opinions and attitudes. Quantitative studies can be used for exploring the impact of DHE on CLD.
- We excluded participants aged less than 18 because there are less DHE interventions directly targeting at children with CLD, but more at their parents, teachers or pediatric-care professionals.
- Studies with no full text cannot provide complete information about their methods, results and conclusions.
- A systematic search (query of experts, professional societies, service providers, etc.) of non-peer-reviewed publications could not be carried out for reasons of research economics.

After removing duplicates, one reviewer (CS) used the open-source machine learning tool ASReview Lab19 (Utrecht University) [22] to screen all the titles and abstracts. Another reviewer (RL) used the Endnote X9 (Clarivate Analytics) to double screen a random proportion of all articles independently. The choice of 15% was made by the reviewer team to ensure the efficiency and reliability of screening based on ASReview developers' recommendation [23] and previously published article that screened the same way [24]. If the agreement rate between the two reviewers was less than 80%, an additional random 15% of all titles and abstracts were screened by RL. Title and abstract screening were stopped only when the agreement rate exceeded 80%. Then, the included articles were selected by screening the full text by CS and HD. CS then screened all references of included articles to identify if extra articles could be included. Any discrepancies during the screening process were solved by achieving consensus or discussing with the review team.

Data Extraction

Reviewer teams (CS, HD, and HW) extracted data with a predesigned standardized data extraction form (Multimedia Appendix 3). Study characteristics (author, publication year, country, profession, study design, sample size, and population levels) were extracted to understand the specific context of each study and assess the relevance, research development and quality. DHE characteristics (type of DHE medium, content, intervention mechanisms, duration, frequency) were extracted to understand what aspect of educational platform, content and behavioral theories were used and how. Outcomes, main findings, and conclusions of included studies were extracted to analyze the impact of DHE on CLD patients.

Data Synthesis

Study characteristics and DHE characteristics were summarized using means and percentages where appropriate. Outcome indicators were summarized in 6 categories. CLD awareness evaluated patients' ability to perceive or to be conscious of CLD or health states (eg, health literacy). Clinical outcomes included physiological and biochemical indicators measured by clinical testing and laboratory equipment (eg, blood pressure, forced expiratory volume [FEV]). Feasibility, acceptability and satisfaction [25] focused on the design or the development of DHE, evaluating the state or degree of being easily or conveniently used, being subject to acceptance, and the expectations, needs, and pleasure of patients. Lifestyle outcomes included diets, sleep, medication adherence, and physical activity. Cost-effectiveness evaluated the cost expenditure of patients or health care systems on the whole process of disease

prevention, treatment, and management. Psychosocial outcomes were observed effects on patients' emotions, well-being, quality of life (QoL), behavior or social interactions [26]. The impacts of DHE were categorized as positive, negative, or no significant difference based on the extracted results and conclusions. Descriptive analysis was used to summarize all the coded data.

Quality Assessment

The Critical Appraisal Skills Program (CASP) checklist was used and adapted for appraising the evidence of different study designs [27]. Following CASP tool recommendations, we classified the evidence quality as high (more than 2/3 of questions are answered by "yes"), moderate (more than 1/3 of questions are answered by "yes") or low (lower than 1/3 of questions are answered by "yes").

Results

Study Characteristics

A total of 22 articles were included in this scoping review (Figure 1), consisting of 19 interventional studies (9 RCTs, 7 quasi-experimental studies and 3 prospective interventional studies) and 3 mixed-method studies. These studies were published between 2000 and 2022 in health care or related professions, showing a distinct increasing trend with the highest number after 2020 (n=11). Details of included articles and the trend of publication year were shown in Multimedia Appendix 3. Among these studies, only 6/22 (27.3%) were conducted in LMICs, with China, India, Indonesia, Lebanon and Iran 1 or 2, respectively (Figure 2). United States accounted for 31.8% (7/22) of these studies among developed countries. The sample size of the studies varied from 15 to 9452 participants, of which the population level ranged from hospitals, clinics to general practices, communities and recruited volunteers. By following CASP checklist, all studies were medium (n=4) to high quality (n=18). Further details can be found in Table 1 and the quality assessment process was described in Multimedia Appendix 4.

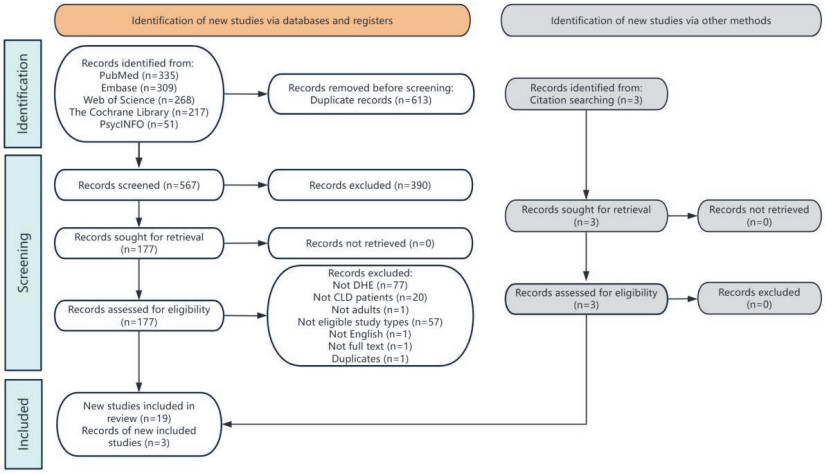


Figure 1 PRISMA-ScR diagram of the review

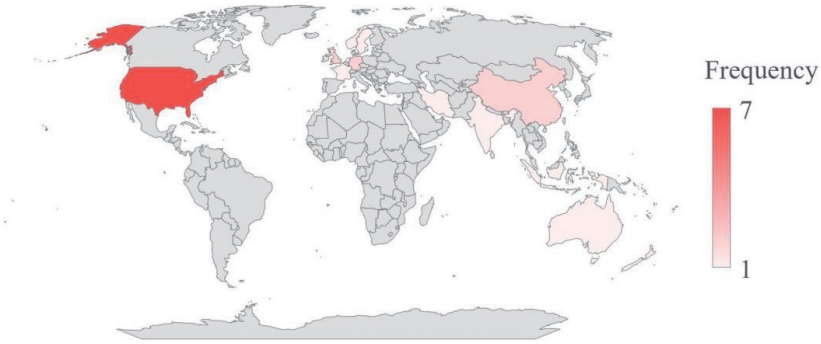


Figure 2 Frequency of publication countries

Table 1 Study characteristics of included articles

Author	Year	Country	Profession	Study design	Sample size	Population levels	Quality assessment
Nyberg et al [28]	2019	Sweden	Community medicine	Quasi-experiment	83 COPD[a] patients	Primary care centers	High
Mongiardo et al [29]	2021	United States	Pulmonary care	Prospective interventional study	72 COPD patients	Outpatient pulmonary clinics	High
Atherton et al [30]	2000	United States	Analytical services	Quasi-experiment	437 asthma patients	MyAsthma users	High
Liu et al [31]	2013	China	Nursing	RCT[b]	60 COPD patients	Volunteer recruitment	Medium
Burns et al [32]	2013	Australia	Health initiatives	Quasi-experiment	51 asthma patients	Online and offline recruitment	High
Wu et al [33]	2017	United States	Public health	Mix-method study	48 CLD[c] patients	General medicine service	High
Farzandipour et al [34]	2019	Iran	Health information	Mix-method study	30 asthma patients, 10 specialists	Clinic	High

Nohra et al [35]	2022	Lebanon	Public health	Quasi-experiment	15 CLD patients	Empirical convenience sample	Medium
Newhouse et al [36]	2016	United Kingdom	Primary care	RCT	148 asthma patients	Primary care practices	Medium
Korsbakke et al [37]	2016	Norway	Health science and technology	RCT	116 COPD patients	Telephone recruitment	Medium
Wan et al [38]	2017	United States	Pulmonary care	RCT	109 COPD patients	General pulmonary clinics	High
Ghozali et al [39]	2022	Indonesia	Pharmacy	RCT	140 asthma patients	Community	High
Kellerer et al [40]	2022	Germany	General practice	Quasi-experiment	72 asthma patients	General practices	High
Hisa et al [41]	2020	United States	Medicine	Prospective interventional study	40 asthma patients	The Montefiore Asthma Center	High
Zhao et al [42]	2020	China	Respiratory medicine	RCT	713 CLD patients	Hospital	High

Hsia et al [43]	2020	United States	Immunology	Prospective interventional study	60 CLD patients	Outpatient multispecialty	High
Schnoor et al [44]	2022	The Netherlands	Public health	Quasi-experiment	9452 CLD patients	Community pharmacies	High
Petrie et al [45]	2012	New Zealand	Psychology	RCT	216 CLD patients	Flyers and emails recruitment	High
Chan et al [46]	2022	India	Immunology	Mixed-method study	57 CLD patients	Clinic	High
Moore et al [47]	2009	United Kingdom	Pulmonary rehabilitation	RCT	20 COPD patients	A program	High
Sobel et al [48]	2009	United States	Internal medicine	Quasi-experiment	130 participants with/without asthma	Organization, education center, clinic	High
Kohler et al [49]	2020	Germany	General practice	RCT	82 asthma patients	Pulmonary rehabilitation clinic	High

[a]COPD: chronic obstructive pulmonary disease.

[b]RCT: randomized controlled trial.

[c]CLD: chronic lung disease.

DHE Mediums, Intervention Mechanism and Contents

Regarding DHE mediums among the 22 studies, 10 (45%) of them were websites or online platforms developed by researchers, along with 6 (27%) studies delivered by mobile applications or tablets, 5 (23%) by video or text messaging, and 1 (4.5%) by MP3 (Table 2). No more than half (9/22, 41%) of studies conducted DHE for over three months. Only 7 studies reported intervention frequency and 4 provided DHE based on "teach-to-go" strategy, Theory of Planned Behavior, and self-regulation.

Table 2 DHE characteristics of included articles

Author	DHE medium	Frequency	Duration	Theory
Nyberg et al [28]	An interactive webpage	NA[a]	6 months	NA
Mongiardo et al [29]	A web-based platform	Daily or weekly	12 months	NA
Atherton et al [30]	www.myasthma.com	NA	6 months	NA
Liu et al [31]	An online animated diagram and video	NA	4 months	NA
Burns et al [32]	An online site	NA	2 months	Theory of Planned Behavior
Wu et al [33]	Virtual learning platform	NA	NA	"teach-to-goal" strategy
Farzandipour et al [34]	A smartphone-based application	NA	1 months	NA

Nohra et al [35]	Powerpoint presentations and videos	Weekly	6 weeks	NA
Newhouse et al [36]	A multimedia website	NA	2 weeks	NA
Korsbakke et al [37]	A tablet	NA	4 weeks	NA
Wan et al [38]	A website	Weekly	3 months	Self-regulation
Ghozali et al [39]	AsmaDroid app	NA	4 weeks	NA
Kellerer et al [40]	A web page	NA	6 months	NA
Hisa et al [41]	ASTHMAXel mobile application	One time use	6 months	NA
Zhao et al [42]	MP3 player	NA	6 months	NA
Hsia et al [43]	ASTHMAXcel mobile application	NA	12 months	NA
Schnoor et al [44]	A web-based platform SARA[b]	NA	12 months	NA
Petrie et al [45]	Text messaging	Irregularly	18 weeks	NA
Chan et al [46]	Adapted ASTHMAXel mobile application	NA	After completing 8 chapters	NA
Moore et al [47]	Video	4 times a week	6 weeks	NA

Sobel et al [48]	Multimedia curriculum	Once	Instantly	"teach-to-goal" strategy
Kohler et al [49]	A website	NA	3 weeks	NA

a: not applicable.

b: Service Apothecary Respiratory Advice.

Different contents of DHE in CLD were summarized and divided into several categories (Multimedia Appendix 5). Self-management skills of CLD (21/22, 95%) were the most common educational content, including managing general CLD condition (20/22, 91%), and exacerbations or asthma attacks (7/22, 32%). Treatment of CLD, disease characteristics, motivational messages or stories were imparted in 15, 15 and 5 studies, respectively. Specifically, medicine or inhaler education (14/22, 64%) was the most frequently mentioned topic about CLD treatment, followed by breathing exercises or physical activity (5/22, 23%) and psychosocial therapy (3/22, 14%).

DHE Outcomes for CLD

After classification and synthesizing, we found 16/22 (73%) studies explored participants' CLD awareness. Clinical outcomes (6/22, 27%), DHE feasibility, acceptability, and satisfaction (8/22, 36%), lifestyle (3/22, 14%), cost-effectiveness (2/22, 9%), and psychosocial outcomes (8/22, 36%) were also reported in different studies.

CLD Awareness

14 out of 16 studies reported positive changes in CLD awareness. Among them, 9 interventional studies noticed a statistically significant increase ($P<.05$) when evaluating CLD knowledge, literacy, and skills in the intervention group compared with the control group [28,32,35,39,40,42,45,48,49]. In a cohort study, Mongiardo et al [29] found a significant improvement in knowledge about exercise, vaccination, inhaled bronchodilators and inhaled steroids ($P<.01$) at 12 months among COPD patients who used a COPD web-based platform that delivers education as part of a physical activity (PA) intervention. Similar results were reported in Hsia's study by measuring Asthma Knowledge Questionnaire scores among asthma patients who used ASTHMAXcel - a novel, guidelines-based smartphone application designed to improve patient education and out-patient management of asthma [41,43]. Chan et al [46] also evaluated an adapted ASTHMAXcel and got the same result using Asthma Knowledge

Questionnaire scores among asthma patients in India. The mean score of patients' self-management knowledge of asthma patients was significantly increased to 4.3 (SD 0.56) (P<.001) after using a smartphone-based application, according to the mixed methods study by Farzandipour et al [34]. When evaluating knowledge and skills after a 6-week home-based educational and telemonitoring program, most of the participants answered correctly [35]. However, Korsbakke et al [37] reported no statistically significant difference in functional health literacy between the intervention and control group when they focused on the effect of the Telekit — a tele-homecare intervention combining a tablet and software that provided information and instructions on managing COPD. No significant differences in COPD knowledge were noted between the pedometer plus website group and the control group in the RCT by Wan et al [38].

Clinical Outcomes

In total, 3 out of 6 studies reported positive clinical outcomes of DHE. These clinical outcomes mainly included change in impact of COPD in daily life evaluated by the COPD Assessment Test [28], FEV, forced expiratory volume in one second (FEV1)/forced vital capacity (FVC), peak expiratory volume, 6-minute walking distance [31], clinical parameters (systolic and diastolic blood pressure, pulse, FEV1, FVC) [37], dyspnea [38], exacerbation rates, antimycotic treatment difference [44], change in walking capacity [47]. In an RCT, COPD patients who received an online animated diagram and video-guided instruction showed significant improvements in FEV, FEV1/FVC, and peak expiratory volume compared with patients who received conventional education (P<.05) [31]. In addition, a significantly lower increase in exacerbation rates over time was found compared to the control participants in asthma participants but not in the COPD population [44]. The walking capacity also showed statistically significant improvements (P<.05) within the intervention group measured by the Incremental Shuttle Walk Test after a home exercise video program among patients with moderate to severe COPD [47]. According to Andre et al [28], however, the mean scores of COPD Assessment Test were not highly reduced in patients with mainly moderate COPD, and the difference is statistically insignificant between the baseline and 3-, 12-month timepoint. There were also RCTs providing information on managing COPD by a tablet and a website with no statistically significant difference in clinical outcomes, although the intervention duration lasted for several weeks and even 3 months [37,38].

DHE Feasibility, Acceptability, and Satisfaction

In total, 6 out of 8 studies indicated a positive effect on DHE feasibility, acceptability and satisfaction. In the study by Nyberg et al [28], the feasibility analysis of a COPD

web page on self-management skills combining texts, pictures, videos, and interactive components was primarily focused on the amount of users and the total time they spent on the site during the initial 3 months, showing that 77% (33/43) of patients having access to the COPD Web were considered users and the average total time on the site was 45 min, which was quite low. Another feasibility study of a novel experience-based internet intervention to support self-management in chronic asthma was also relatively low, reporting that the median number of logins during 2 weeks was 2, and the median amount of time spent on the site was 17 minutes [36]. In addition, the e-Health Impact Questionnaire scores they used to measure the respondents' attitudes toward the website were quite similar between groups. Satisfaction, ease-of-use and usefulness were assessed when analyzing the acceptability of an education website AsthmaWise for older asthma adults, of which 68.6% (35/51) had decided to visit it to learn more about how to manage their asthma, 94.1% (48/51) found it useful and almost all participants would recommend it to others [32]. Wu et al [33] developed a virtual teach-to-goal inhaler technique learning module and found that over 80% (39/48) reported that they were likely to use it to gain skills to improve their health. Furthermore, they identified several domains from focus group for optimal patient use: access, functionality, and quality. In a quasi-experiment, all 15 participants considered the educational and telemonitoring program adequate and acceptable, declaring they had no difficulty explaining to others and would suggest to others [35]. The satisfaction rate regarding an audio-educational method (81.51% (291/357) vs 66.01% (235/356), $P<.05$) and effective feedback (82.93% (68/82) vs 52.50% (42/80), $P<.001$) were significantly higher in the experimental group than in the control group for patients from respiratory medicine wards [42]. Patients were highly satisfied in the ASTHMAXcel group, scoring on average 27.9/30 points on the satisfaction survey, but no difference was found in either intervention [43]. An average of 50 out of 54 maximum points was noted based on the Questionnaire for User Interface Satisfaction about participants' postinterventional median satisfaction for the adapted ASTHMAXcel [46].

Lifestyle

All (3/3) studies reported positive changes in patients' lifestyle. When evaluating the effect of a COPD web in promoting self-management of patients, the amount of daily physical activity and time spent in training exercises in the intervention group at 3 months was increased compared with the usual care group, but not statistically different at 12 months [28]. The daily step count in the pedometer plus website group also significantly improved from baseline beginning and maintained to week 13 based on the theory of self-regulation [38]. When comparing medication adherence in the year

after the implementation of an eHealth intervention - Service Apothecary Respiratory Advice (SARA), both study groups showed an increase in mean medication adherence over time. Especially, it was significantly higher for SARA participants (*P*=.01), according to Schnoor et al [44].

Cost-Effectiveness Outcomes

Only two studies evaluated the cost-effectiveness outcomes of DHE. A study conducted in Lebanon estimated the overall cost of the educational and telemonitoring program was 200 USD/patient (educational sessions only) and US $244 per patient (including telemonitoring services), which consisted of the general cost of materials or patients, time nurses spent on patients, hospitalizations and emergency room visits [35]. However, it was difficult for them to evaluate this intervention's relative cost given the complicated economic situation in Lebanon. The other study reported that all health care utilization endpoints, including asthma-related emergency department visits, hospitalizations, and oral prednisone use, decreased at 4 months and 6 months based on survey results [41].

Psychosocial Outcomes

Improved psychosocial outcomes were reported in 7 out of 8 studies. Notably, QoL, usually evaluated by self-reported questionnaire, was the most frequent outcome in these studies. In total, 7 out of 8 studies reported improvement in the intervention group or at the follow-up point [30,31,35,36,38,41,47]. A total of 5 of 15 patients showed lower anxiety and depression scores, and 6 had higher QoL scores compared to baseline measures, according to Rita's study [35]. Minimal differences of change from baseline between groups were noticed regarding how well asthma patients manage their condition and self-efficacy of being able to undertake certain activities [36]. Wan et al [38] also compared health related QoL, exercise self-efficacy, depression, social support, motivation, and confidence to exercise, but no significant differences were noted between groups. All participants showed an increase in health state from baseline based on the Physical and Mental component of the SF36 (including physical and mental dimensions), with a more significant improvement in the intervention group that provided a multimedia website illustrating asthma-related information [36]. No other psychosocial outcomes were analyzed in these studies.

Discussion

Principal Findings

Current evidence presents comprehensive characteristics and the potentially positive impact of DHE on CLD. A total of 22 published studies with medium to high quality from 2000 to 2022 were analyzed in this review, including 9 (41%) RCTs, 7 (32%) quasi-experimental studies, 3 (14%) mixed-method studies, and 3 (14%) prospective interventional studies. Most studies (16/22, 73%) were conducted in developed countries. Websites and mobile applications (10/22, 45%) were the most widely used medium to conduct DHE among CLD patients, followed by mobile applications or tablets, video or text messaging, and MP3. Participants were mainly CLD patients recruited from hospitals and general practices. No more than half of these studies (9/22, 41%) implemented DHE interventions for more than 3 months, and few (3/22, 14%) were based on theoretical mechanisms when educating the target population. The DHE content varied from a general introduction of CLD characteristics (definition and etiology), treatment to self-management skills of CLD, motivational messages and stories for patients and their relatives. Positive impacts were reported among most of these studies, including increased CLD awareness (14/16, 88%), clinical (3/6, 50%), lifestyle (3/3, 100%), psychosocial outcomes (7/8, 88%) and impressive feasibility, satisfaction and acceptability (6/8, 75%). Only two studies reported cost-effectiveness outcomes.

Comparison with Previous Work

The growing number of publications pertaining to DHE in CLD and the widespread use of websites and mobile applications shed light on an increasingly important role of digital technology in health and healthcare. As of January 2023, there were 5.16 billion internet users worldwide, over 60% of the global population currently connected to the world wide web with an estimated 192 minutes per day per user spent online [50]. In addition, integrating digital technology in health care is revolutionary by providing easy access to health services, improving patient engagement, supporting remote supervision of physical activity regimes at home, delivering timely detection of deteriorating health status, and serving as a cost-saving alternative health service [51]. Although not mentioned in included studies, the integration of artificial technology (AI) in health care, which is another promising DHE medium, holds a significant potential to deliver more efficient and personalized educational content through advanced algorithm and predictive analytics [52,53]. Therefore, users could access a diverse range of health information with better accessibility, efficiency and interactivity. The increasing trend of exploring the impacts of DHE intervention will continue in future research.

More attention should be paid to implementing and scaling DHE to LMICs and the general population with limited access to digital technology. As reported, the internet penetration rate of China was relatively low at 76% compared with South Korea and Japan, which ranged over the 90% mark, although it is home to the largest digital community in the world, with about 1.07 billion netizens as of 2022 [54]. The same pattern is apparent in Southeast Asian countries with little internet accessibility at home and low self-perceived digital literacy among Southeast Asian youth, hereby reducing health care engagement and hindering health information dissemination for the local people [55]. Larger gains in health can be achieved in these areas due to the huge population underserved, which could also contribute to global health in the future. Furthermore, new opportunities and challenges are presented when scaling up DHE with the increasing ageing population and worldwide health problems. Digital technologies play an increasingly important role not only in health education and promotion but also in addressing issues of health equality [56].

Future studies should further elucidate DHE characteristics and mechanisms to ensure long-standing effectiveness and verifiable impacts. First, the predominance of DHE contents focusing on self-management skills of CLD highlights the importance of empowering individuals to take an active role in their own health, which corresponds to the current research trends of chronic diseases [57,58]. Second, successful health education depends on repeatedly using a few messages of proven benefit and in many forums [59]. As such, the DHE content and the authenticity of contents should be warranted, of which the latter was rarely mentioned. As an essential health education component, DHE frequency, duration and intervention theories are closely connected with prospective health outcomes. Several existing models, such as the Unified Theory of Acceptance and Use of Technology, Technology Acceptance Model, Social Cognitive Theory and Theory of Planned Behavior, have been identified as facilitators to adopting digital health interventions [60]. Specifically, interventions based on the theory of planned behavior tended to have more substantial effects on behavior compared to interventions incorporating fewer techniques [61]. In this review, however, few studies illuminated the frequency (7/22, 31%) and intervention theory (4/22, 18%), indicating a potential gap in understanding how DHE interventions work and the underlying mechanisms that impact CLD patients and related outcomes.

The effects reported on awareness or knowledge are commonly acknowledged [62-64] because digital technologies can support a wide range of self-directed learning activities, providing learners with diverse resources, information, and network resources that meet

their learning needs [9]. Improvement of clinical outcomes suggests the potential of DHE to empower patients to make informed decisions about their health, adhere to treatment regimens, and adopt healthier lifestyles after enhancing their understanding of disease and health conditions. Similar positive effects in QoL and health status were also reported in other reviews, but they mainly focus on digital health interventions [65,66]. Insignificant effects in several studies might be related to the intervention duration or inclusion of participants [37,38,44]. The reported impacts on DHE feasibility, acceptability, and satisfaction shed light on users' active engagement and willingness with these interventions. These positive findings align with other studies [67,68], indicating that DHE is generally well-received by individuals with CLD and implies promising practicality and scalability in real-world settings.

A limited number of studies reported impacts on lifestyle (n=3) and cost-effectiveness outcomes (n=2) in this review, which needs more evidence to illustrate in the future. The lifestyle outcomes extracted from the included studies were limited to physical activity and medication adherence. According to previous studies, however, a sedentary and unhealthy lifestyle, including smoking, having an unhealthy diet and insufficient exercise could fuel chronic disease progression by changing interstitial cell behavior [69]. In addition, we noticed that only one study applied behavioral theories but implemented DHE for only 2 months when exploring DHE impacts on lifestyle [32]. However, evidence has shown that a successful digital intervention can influence lifestyle management [70], and the theory of behavior change maintenance can guide the development and evaluation of interventions, thereby promoting sustained change in health behavior and lifestyles [71]. As such, a deeper exploration of specific lifestyles, such as the dietary pattern, types, frequencies and intensities of exercise and other health-related outcomes should be mapped, with validated and effective theories. Currently, few studies in this review compare the cost or health care utilization after DHE intervention, which guided future cost-effectiveness studies with more accurate and complete data to fill in the gap.

Recommendation on Future Research

Based on the current review, we recommend that future research and development in DHE for people with CLD should focus on elucidating the characteristics and mechanisms of the DHE intervention, prioritizing less developed areas, investigating more lifestyle or behavioral outcomes, evaluating cost-effectiveness among different DHE mediums and ensuring long-term sustainability, to ultimately improve the

effectiveness, scalability of DHE, and the health status of CLD patients. With the integration of AI in health care, we hope to see more personalized and efficient education content delivered and look forward to studies reporting its potential and effectiveness. Given that several studies were of medium quality based on the CASP tool, we recommend future researchers consider incorporating blinding among participants, investigators and analysts, as well as addressing confounding factors in both study design and analysis, which will enhance the robustness and reliability.

Strengths and Limitations

This is the first review to explore the characteristics and impact of DHE on CLD. Diverse studies in this review were synthesized and analyzed under the PRISMA-ScR guideline, all showing medium or high-quality evidence with a practical quality assessment tool. The detailed descriptions of DHE and its impact on different outcomes provide an important theoretical basis and new thoughts for further research in DHE. However, this review included studies focusing more on mixed digital health intervention. Despite the potential benefits, whether it is the independent or compounding influence of DHE remains to be discussed further due to the inability of subgroup analysis. The incomplete screening of titles and abstracts by the second reviewer may have introduced potential bias into the review process. The exclusion of non-English articles and studies without full text access could result in publication bias to some extent. In addition, it is worth mentioning the caution of extrapolating the impact to other DHE mediums, despite recognizing the reliability of health information in these studies. Variations in researchers' professions might also contribute to heterogeneity in study implementation and reporting.

Conclusion

Despite the heterogeneity of the study situation, some aspects can be concluded. Digital health education can improve disease awareness and clinical outcomes among chronic lung disease patients with good feasibility, acceptability and satisfaction through different medium and educational content. There is still relative limited research among people in low- and middle-income countries. Future research should consider the impacts on cost-effectiveness outcomes, duration, frequency, and theoretical mechanism of the DHE intervention to maximize the potential effects. It should also be conducted in the context of health services research to better reflect the real-world settings.

Abbreviations

AI: artificial intelligence
CASP: The Critical Appraisal Skills Program checklist
CLD: chronic lung disease
COPD: chronic obstructive pulmonary disease
DHE: Digital health education
FEV: forced expiratory volume
FEV1: forced expiratory volume in one second
FVC: forced vital capacity
LMIC: low- and middle-income countries
PICO: Participants, Intervention, Comparator, and Outcomes
PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Review
QoL: quality of life
RCT: randomized control test
SARA: Service Apothecary Respiratory Advice

Multimedia appendixes

Scan the QR code to access the full version of all appendixes.



References

1. Chronic respiratory diseases. World Health Organization. 2023. [2023-05-06]. https://www.who.int/health-topics/chronic-respiratory-diseases.

2. GBD Chronic Respiratory Disease Collaborators Prevalence and attributable health burden of chronic respiratory diseases, 1990-2017: a systematic analysis for the Global Burden of Disease Study 2017. Lancet Respir Med. 2020;8(6):585–596. doi: 10.1016/S2213-2600(20)30105-3.S2213-2600(20)30105-3

3. Li X, Cao X, Guo M, Xie M, Liu X. Trends and risk factors of mortality and disability adjusted life years for chronic respiratory diseases from 1990 to 2017: systematic analysis for the global burden of disease study 2017. BMJ. 2020;368:m234. doi: 10.1136/bmj.m234.

4. Safiri S, Carson-Chahhoud K, Noori M, Nejadghaderi SA, Sullman MJM, Ahmadian Heris J, Ansarin K, Mansournia MA, Collins GS, Kolahi A, Kaufman JS. Burden of chronic obstructive pulmonary disease and its attributable risk factors in 204 countries and territories, 1990-2019: results from the global burden of disease study 2019. BMJ. 2022;378:e069679. doi: 10.1136/bmj-2021-069679.

5. Rabe KF, Watz H. Chronic obstructive pulmonary disease. Lancet. 2017;389(10082):1931–1940. doi: 10.1016/S0140-6736(17)31222-9.

6. Iheanacho I, Zhang S, King D, Rizzo M, Ismaila AS. Economic burden of chronic obstructive pulmonary disease (COPD): a systematic literature review. Int J Chron Obstruct Pulmon Dis. 2020;15:439–460. doi: 10.2147/COPD.S234942.

7. Bajpai S, Semwal M, Bajpai R, Car J, Ho AHY. Health professions' digital education: review of learning theories in randomized controlled trials by the digital health education collaboration. J Med Internet Res. 2019;21(3):e12912. doi: 10.2196/12912.

8. Stern AD, Brönneke Jan, Debatin JF, Hagen J, Matthies H, Patel S, Clay I, Eskofier B, Herr A, Hoeller K, Jaksa A, Kramer DB, Kyhlstedt M, Lofgren KT, Mahendraratnam N, Muehlan H, Reif S, Riedemann L, Goldsack JC. Advancing digital health applications: priorities for innovation in real-world evidence generation. Lancet Digit Health. 2022;4(3):e200–e206. doi: 10.1016/S2589-7500(21)00292-2.

9. Curran V, Matthews L, Fleet L, Simmons K, Gustafson DL, Wetsch L. A review of digital, social, and mobile technologies in health professional education. J Contin Educ Health Prof. 2017;37(3):195–206. doi: 10.1097/CEH.0000000000000168.

10. Baumgart DC. Smartphones in clinical practice, medical education, and research. Arch Intern Med. 2011;171(14):1294–1296. doi: 10.1001/archinternmed.2011.320.

11. Han ER, Yeo S, Kim MJ, Lee YH, Park KH, Roh H. Medical education trends for future physicians in the era of advanced technology and artificial intelligence: an integrative

review. BMC Med Educ. 2019;19(1):460. doi: 10.1186/s12909-019-1891-5.

12. Kaihara T, Scherrenberg M, Intan-Goey V, Falter M, Kindermans H, Frederix I, Dendale P. Efficacy of digital health interventions on depression and anxiety in patients with cardiac disease: a systematic review and meta-analysis. Eur Heart J Digit Health. 2022;3(3):445–454. doi: 10.1093/ehjdh/ztac037.

13. Howarth A, Quesada J, Silva J, Judycki S, Mills PR. The impact of digital health interventions on health-related outcomes in the workplace: a systematic review. Digit Health. 2018;4 doi: 10.1177/2055207618770861.

14. Absolom K, Warrington L, Hudson E, Hewison J, Morris C, Holch P, Carter R, Gibson A, Holmes M, Clayton B, Rogers Z, McParland L, Conner M, Glidewell L, Woroncow B, Dawkins B, Dickinson S, Hulme C, Brown J, Velikova G. Phase III randomized controlled trial of eRAPID: eHealth intervention during chemotherapy. J Clin Oncol. 2021;39(7):734–747. doi: 10.1200/JCO.20.02015.

15. Wagner LI, Tooze JA, Hall DL, Levine BJ, Beaumont J, Duffecy J, Victorson D, Gradishar W, Leach J, Saphner T, Sturtz K, Smith ML, Penedo F, Mohr DC, Cella D. Targeted eHealth intervention to reduce breast cancer survivors' fear of recurrence: results from the foRtitude randomized trial. J Natl Cancer Inst. 2021;113(11):1495–1505. doi: 10.1093/jnci/djab100.

16. Adisa R, Ufuah UF, Ige OM. Impact of pharmacist-led intervention in medication adherence and inhaler usage on asthma and chronic obstructive pulmonary disease control: a quasi-experimental study. BMC Health Serv Res. 2024;24(1):1199. doi: 10.1186/s12913-024-11683-9.

17. Rasulnia M, Burton BS, Ginter RP, Wang TY, Pleasants RA, Green CL, Lugogo N. Assessing the impact of a remote digital coaching engagement program on patient-reported outcomes in asthma. J Asthma. 2018;55(7):795–800. doi: 10.1080/02770903.2017.1362430.

18. Arnaert A, Ahmad H, Mohamed S, Hudson E, Craciunas S, Girard A, Debe Z, Dantica JL, Denoncourt C, Côté-Leblanc G. Experiences of patients with chronic obstructive pulmonary disease receiving integrated telehealth nursing services during COVID-19 lockdown. BMC Nurs. 2022;21(1):205. doi: 10.1186/s12912-022-00967-2.

19. Kuhn L, Reeves K, Taylor Y, Tapp H, McWilliams A, Gunter A, Cleveland J, Dulin M. Planning for action: the impact of an asthma action plan decision support tool integrated into an electronic health record (EHR) at a large health care system. J Am Board Fam Med. 2015;28(3):382–393. doi: 10.3122/jabfm.2015.03.140248.

20. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, Moher D, Peters MDJ, Horsley T, Weeks L, Hempel S, Akl EA, Chang C, McGowan J, Stewart L, Hartling L, Aldcroft A, Wilson MG, Garritty C, Lewin S, Godfrey CM, Macdonald MT,

Langlois EV, Soares-Weiser K, Moriarty J, Clifford T, Tunçalp Ö, Straus SE. PRISMA Extension for scoping reviews (PRISMA-ScR): checklist and explanation. Ann Intern Med. 2018;169(7):467–473. doi: 10.7326/M18-0850.

21. da Costa Santos CM, de Mattos Pimenta CA, Nobre MRC. The PICO strategy for the research question construction and evidence search. Rev Lat Am Enfermagem. 2007;15(3):508–511. doi: 10.1590/s0104-11692007000300023.

22. van de Schoot R, de Bruin J, Schram R, Zahedi P, de Boer J, Weijdema F, Kramer B, Huijts M, Hoogerwerf M, Ferdinands G, Harkema A, Willemsen J, Ma Y, Fang Q, Hindriks S, Tummers L, Oberski DL. An open source machine learning framework for efficient and transparent systematic reviews. Nat Mach Intell. 2021;3(2):125–133. doi: 10.1038/s42256-020-00287-7.

23. Penfornis KM, Van Vliet MHM, Meijer E, Gebhardt WA. Mapping the evidence on identity processes and identity-related interventions in the smoking and physical activity domains: a scoping review protocol. BMJ Open. 2022;12(7):e058405. doi: 10.1136/bmjopen-2021-058405.

24. Westendorp J, Geerse OP, van der Lee ML, Schoones JW, van Vliet MHM, Wit T, Evers AWM, van Vliet LM. Harmful communication behaviors in cancer care: a systematic review of patients and family caregivers perspectives. Psychooncology. 2023;32(12):1827–1838. doi: 10.1002/pon.6247.

25. Hamine S, Gerth-Guyette E, Faulx D, Green BB, Ginsburg AS. Impact of mHealth chronic disease management on treatment adherence and patient outcomes: a systematic review. J Med Internet Res. 2015;17(2):e52. doi: 10.2196/jmir.3951.

26. Bourne P, Camic PM, Crutch SJ. Psychosocial outcomes of dyadic arts interventions for people with a dementia and their informal caregivers: a systematic review. Health Soc Care Community. 2021;29(6):1632–1649. doi: 10.1111/hsc.13267.

27. Critical Appraisal Skills Programme. 2022. [2023-05-10]. https://casp-uk.net/casp-tools-checklists/.

28. Nyberg A, Tistad M, Wadell K. Can the COPD web be used to promote self-management in patients with COPD in swedish primary care: a controlled pragmatic pilot trial with 3 month- and 12 month follow-up. Scand J Prim Health Care. 2019;37(1):69–82. doi: 10.1080/02813432.2019.1569415.

29. Mongiardo MA, Robinson SA, Finer EB, Cruz Rivera PN, Goldstein RL, Moy ML. The Effect of a web-based physical activity intervention on COPD knowledge: a secondary cohort study. Respir Med. 2021;190:106677. doi: 10.1016/j.rmed.2021.106677.

30. Atherton M. Outcome measures of efficacy associated with a web-enabled asthma self-

management programme: findings from a quasi-experiment. Disease Management and Health Outcomes. 2000;8(4):233–242.

31. Liu F, Cai H, Tang Q, Zou Y, Wang H, Xu Z, Wei Z, Wang W, Cui J. Effects of an animated diagram and video-based online breathing program for dyspnea in patients with stable COPD. Patient Prefer Adherence. 2013;7:905–913. doi: 10.2147/PPA.S43305.

32. Burns P, Jones SC, Iverson D, Caputi P. AsthmaWise - a field of dreams? The results of an online education program targeting older adults with asthma. J Asthma. 2013;50(7):737–744. doi: 10.3109/02770903.2013.799688.

33. Wu M, Woodrick NM, Arora VM, Farnan JM, Press VG. Developing a virtual teach-to-goal inhaler technique learning module: a mixed methods approach. J Allergy Clin Immunol Pract. 2017;5(6):1728–1736. doi: 10.1016/j.jaip.2017.04.032.

34. Farzandipour M, Nabovati E, Arani MH, Akbari H, Sharif R, Anvari S. Enhancing asthma patients' self-management through smartphone-based application: design, usability evaluation, and educational intervention. Appl Clin Inform. 2019;10(5):870–878. doi: 10.1055/s-0039-1700866.

35. Nohra RG, Chaaban T, Sacre H, Salameh P, Aoun Bacha Z, Le Bon Chami B, Abou Rizk F, Makhlouf P, Rothan-Tondeur M. Evaluating the feasibility and pretesting the impact of an educational and telemonitoring program for COPD patients in Lebanon. Int J Chron Obstruct Pulmon Dis. 2022;17:949–965. doi: 10.2147/COPD.S339592.

36. Newhouse N, Martin A, Jawad S, Yu L, Davoudianfar M, Locock L, Ziebland S, Powell J. Randomised feasibility study of a novel experience-based internet intervention to support self-management in chronic asthma. BMJ Open. 2016;6(12):e013401. doi: 10.1136/bmjopen-2016-013401.

37. Korsbakke Emtekaer Haesum L, Ehlers L, Hejlesen OK. Interaction between functional health literacy and telehomecare: short-term effects from a randomized trial. Nurs Health Sci. 2016;18(3):328–333. doi: 10.1111/nhs.12272.

38. Wan ES, Kantorowski A, Homsy D, Teylan M, Kadri R, Richardson CR, Gagnon DR, Garshick E, Moy ML. Promoting physical activity in COPD: insights from a randomized trial of a web-based intervention and pedometer use. Respir Med. 2017;130:102–110. doi: 10.1016/j.rmed.2017.07.057.

39. Ghozali MT, Satibi S, Ikawati Z, Lazuardi L. The efficient use of smartphone apps to improve the level of asthma knowledge. J Med Life. 2022;15(5):625–630. doi: 10.25122/jml-2021-0367.

40. Kellerer C, Schultz K, Linde K, Kohler B, Hapfelmeier A, Schneider A. Implementation of an internet-based asthma patient education program in primary care:

results of a single-arm trial. J Asthma. 2022;60(1):195–202. doi: 10.1080/02770903.2022.2040027.

41. Hsia BC, Wu S, Mowrey WB, Jariwala SP. Evaluating the ASTHMAXcel mobile application regarding asthma knowledge and clinical outcomes. Respir Care. 2020;65(8):1112–1119. doi: 10.4187/respcare.07550.

42. Zhao Y, Liu M, Fan Z, Li J, Shi L, Zhang Y, Gong Y, Yang W. Application of audio education in respiratory medicine wards. Clin Nurs Res. 2020;29(6):392–397. doi: 10.1177/1054773819829622.

43. Hsia B, Mowrey W, Keskin T, Wu S, Aita R, Kwak L, Ferastraoarou D, Rosenstreich D, Jariwala SP. Developing and pilot testing ASTHMAXcel, a mobile app for adults with asthma. J Asthma. 2020;58(6):834–847. doi: 10.1080/02770903.2020.1728770.

44. Schnoor K, Versluis A, Bakema R, van Luenen S, Kooij MJ, van den Heuvel JM, Teichert M, Honkoop PJ, van Boven JFM, Chavannes NH, Aardoom JJ. A pharmacy-based eHealth intervention promoting correct use of medication in patients with asthma and COPD: nonrandomized pre-post study. J Med Internet Res. 2022;24(6):e32396. doi: 10.2196/32396.

45. Petrie KJ, Perry K, Broadbent E, Weinman J. A text message programme designed to modify patients' illness and treatment beliefs improves self-reported adherence to asthma preventer medication. Br J Health Psychol. 2012;17(1):74–84. doi: 10.1111/j.2044-8287.2011.02033.x.

46. Chan A, Kodali S, Lee GY, Gadhave S, Feldman JM, Arora S, Pawar S, Gadkari R, Bargaje M, Salvi S, Jariwala SP. Evaluating the effect and user satisfaction of an adapted and translated mobile health application ASTHMAXcel© among adults with asthma in Pune, India. J Asthma. 2023;60(8):1513–1523. doi: 10.1080/02770903.2022.2155188.

47. Moore J, Fiddler H, Seymour J, Grant A, Jolley C, Johnson L, Moxham J. Effect of a home exercise video programme in patients with chronic obstructive pulmonary disease. J Rehabil Med. 2009;41(3):195–200. doi: 10.2340/16501977-0308.

48. Sobel RM, Paasche-Orlow MK, Waite KR, Rittner SS, Wilson EAH, Wolf MS. Asthma 1-2-3: a low literacy multimedia tool to educate African American adults about asthma. J Community Health. 2009;34(4):321–327. doi: 10.1007/s10900-009-9153-9.

49. Kohler B, Kellerer C, Schultz K, Wittmann M, Atmann O, Linde K, Hapfelmeier A, Schneider A. An internet-based asthma self-management program increases knowledge about asthma. Dtsch Arztebl Int. 2020;117(5):64–71. doi: 10.3238/arztebl.2020.0064.

50. Number of internet and social media users worldwide as of January. 2023. [2023-05-13]. https://www.statista.com/statistics/617136/digital-population-worldwide/.

51. Ramachandran HJ, Oh JL, Cheong YK, Jiang Y, Teo JYC, Seah CWA, Yu M, Wang W. Barriers and facilitators to the adoption of digital health interventions for COPD management: a scoping review. Heart Lung. 2023;59:117–127. doi: 10.1016/j.hrtlng.2023.02.004.

52. Koo TH, Zakaria AD, Ng JK, Leong XB. Systematic review of the application of Artificial intelligence in healthcare and nursing care. Malays J Med Sci. 2024;31(5):135–142. doi: 10.21315/mjms2024.31.5.9.

53. Issa WB, Shorbagi A, Al-Sharman A, Rababa M, Al-Majeed K, Radwan H, Refaat Ahmed F, Al-Yateem N, Mottershead R, Abdelrahim DN, Hijazi H, Khasawneh W, Ali I, Abbas N, Fakhry R. Shaping the future: perspectives on the integration of artificial intelligence in health profession education: a multi-country survey. BMC Med Educ. 2024;24(1):1166. doi: 10.1186/s12909-024-06076-9.

54. Thomala LL. Internet usage in China - statistics & facts. Statista. [2023-05-13]. https://www.statista.com/topics/1179/internet-usage-in-china/#topicOverview.

55. Kameke LV. Internet usage in Southeast Asia - statistics & facts. 2023. [2023-05-13]. URL: https://www.statista.com/topics/9093/internet-usage-in-southeast-asia/#topicOverview.

56. Thompson M. The geographies of digital health - digital therapeutic landscapes and mobilities. Health Place. 2021;70:102610. doi: 10.1016/j.healthplace.2021.102610.

57. Murphy LA, Harrington P, Taylor SJ, Teljeur C, Smith SM, Pinnock H, Ryan M. Clinical-effectiveness of self-management interventions in chronic obstructive pulmonary disease: an overview of reviews. Chron Respir Dis. 2017;14(3):276–288. doi: 10.1177/1479972316687208.

58. Allegrante JP, Wells MT, Peterson JC. Interventions to support behavioral self-management of chronic diseases. Annu Rev Public Health. 2019;40:127–146. doi: 10.1146/annurev-publhealth-040218-044008.

59. Loevinsohn BP. Health education interventions in developing countries: a methodological review of published articles. Int J Epidemiol. 1990;19(4):788–794. doi: 10.1093/ije/19.4.788.

60. Schreiweis B, Pobiruchin M, Strotbaum V, Suleder J, Wiesner M, Bergh B. Barriers and facilitators to the implementation of eHealth services: systematic literature analysis. J Med Internet Res. 2019;21(11):e14197. doi: 10.2196/14197.

61. Webb TL, Joseph J, Yardley L, Michie S. Using the internet to promote health behavior change: a systematic review and meta-analysis of the impact of theoretical basis, use of behavior change techniques, and mode of delivery on efficacy. J Med Internet Res. 2010;12(1):e4. doi: 10.2196/jmir.1376.

62. Martinengo L, Yeo NJY, Markandran KD, Olsson M, Kyaw BM, Car LT. Digital health professions education on chronic wound management: a systematic review. Int J Nurs Stud. 2020;104:103512. doi: 10.1016/j.ijnurstu.2019.103512.

63. Cueva M, Kuhnley R, Revels L, Schoenberg NE, Dignan M. Digital storytelling: a tool for health promotion and cancer awareness in rural alaskan communities. Int J Circumpolar Health. 2015;74:28781. doi: 10.3402/ijch.v74.28781.

64. Soloe C, Burrus O, Subramanian S. The effectiveness of mHealth and eHealth tools in improving provider knowledge, confidence, and behaviors related to cancer detection, treatment, and survivorship care: a systematic review. J Cancer Educ. 2021;36(6):1134–1146. doi: 10.1007/s13187-021-01961-z.

65. McCabe C, McCann M, Brady AM. Computer and mobile technology interventions for self-management in chronic obstructive pulmonary disease. Cochrane Database Syst Rev. 2017;5(5):CD011425. doi: 10.1002/14651858.CD011425.pub2.

66. Yin AL, Hachuel D, Pollak JP, Scherl EJ, Estrin D. Digital health apps in the clinical care of inflammatory bowel disease: scoping review. J Med Internet Res. 2019;21(8):e14630. doi: 10.2196/14630.

67. Brands MR, Gouw SC, Beestrum M, Cronin RM, Fijnvandraat K, Badawy SM. Patient-centered digital health records and their effects on health outcomes: systematic review. J Med Internet Res. 2022;24(12):e43086. doi: 10.2196/43086.

68. Skogberg M, Mackiewicz K, Mänd K, Tuuling L, Urdzina-Merca I, Salanterä S, Pakarinen A. Promoting the health and wellbeing of children: a feasibility study of a digital tool among professionals. PLoS One. 2022;17(3):e0265355. doi: 10.1371/journal.pone.0265355.

69. Huston P. A sedentary and unhealthy lifestyle fuels chronic disease progression by changing interstitial cell behaviour: a network analysis. Front Physiol. 2022;13:904107. doi: 10.3389/fphys.2022.904107.

70. Chatterjee A, Prinz A, Gerdes M, Martinez S. Digital interventions on healthy lifestyle management: systematic review. J Med Internet Res. 2021;23(11):e26931. doi: 10.2196/26931.

71. Kwasnicka D, Dombrowski SU, White M, Sniehotta F. Theoretical explanations for maintenance of behaviour change: a systematic review of behaviour theories. Health Psychol Rev. 2016;10(3):277–296. doi: 10.1080/17437199.2016.1151372.

Chapter 6

Effects of illness perceptions and eHealth literacy on effectiveness of a digital inhaler program for asthma in the Netherlands: post-hoc moderation analyses of a cluster randomized controlled trial

Chao Sun, Marise J. Kasteleyn, Job F.M. van Boven, Yoran H. Gerritsma, Janwillem W.H. Kocks, Charlotte C. Poot, Susanne J. van de Hei, Liselot van den Berg, Niels H. Chavannes, Eline Meijer

JMIR mHealth and uHealth (under review)

Abstract

Background

Digital inhalers can improve medication adherence and asthma control, but their effectiveness might vary among patients. Illness perceptions and eHealth literacy (eHL) may influence how individuals use them, yet little is known about their impact.

Objectives

This study aims to explore: 1) whether illness perceptions and eHL moderate effectiveness of a digital inhaler program in terms of medication adherence and asthma control, and 2) associations between demographics, illness perceptions and eHL.

Methods

This is a post-hoc analysis of the 12-month cluster randomized controlled trial. Participants with suboptimally controlled asthma were recruited in Dutch primary care. The intervention group used a digital inhaler program for self-monitoring and reminders of medication adherence. The control group used a passively monitored inhaler without feedback. Main outcomes were medication adherence, objectively measured by an electronic monitoring device, and asthma control measured with the Asthma Control Questionnaire (ACQ). Moderator variables were illness perceptions and eHL, measured by the Brief Illness Perception Questionnaire (B-IPQ) and eHealth Literacy Questionnaire (eHLQ), respectively. Mixed-effects models and multivariable linear regression analyses were conducted.

Results

A total of 164 asthma patients were included. Mean B-IPQ and eHLQ scores were 35.0 (SD 8.2) and 100.3 (SD 13.5), demonstrating relatively positive perceptions of asthma and a medium level of eHL. No significant moderation effects of illness perceptions and eHL were found on medication adherence and asthma control ($p>0.05$). Younger age was associated with higher eHL ($b=-0.3$, $p<0.01$).

Conclusion

The digital inhaler program can improve medication adherence and asthma control regardless of illness perceptions and eHL levels of asthma patients. Overall, younger patients showed higher eHL. Future studies should consider intervention elements, mechanisms and gain qualitative insights into users' experiences to make eHealth interventions effective and equitable across diverse populations, while prioritizing accessibility, good usability, acceptability, and inclusiveness during the design process.

Introduction

Asthma is a common chronic lung disease characterized by airway inflammation and narrowing [1], affecting 262 million people and causing 455,000 deaths worldwide in 2019 [2]. Despite the availability of treatments, poor medication adherence, the extent to which a person's behavior corresponds with the agreed recommendations of a healthcare professional (HCP) [3], remains a persistent barrier in asthma care, contributing to increased exacerbations and healthcare utilization [4, 5]. Digital inhalers, incorporating inhaler devices and connected sensors linked to web or mobile applications to support inhaler usage [6], have demonstrated effectiveness in improving asthma medication adherence [7-9]. According to the COM-B model [10], a behavioral theory that has been applied in previous studies of implementation strategies in asthma care [11, 12], individuals' motivation and capability are two important components for effective behavior change [13], and may (in)directly influence medication adherence. Therefore, individual patient factors should be considered to ensure equitable effectiveness of digital inhalers.

One such patient factor is illness perceptions, reflecting individuals' cognitive (e.g., consequences, timeline personal control) and emotional representations (e.g., concerns, emotions) of the illness [14]. Notably, a previous study in asthma patients showed that those with more negative illness perceptions had more severe symptoms, poorer asthma control and higher levels of anxiety and depression [15]. Similarly, other studies showed that patients who perceive their illness as more controllable are more likely to adhere to medication regimens and have better quality of life [16, 17]. Therefore, differences in illness perceptions may influence how patients interpret their symptoms, shaping their motivations to engage with digital inhalers and take more actions, and potentially affecting the strength of intervention effects.

Another potentially relevant factor is eHealth literacy (eHL) — the capability to seek, find, understand, and appraise health information from digital technology and apply it to address health issues [18]. As internet and mobile devices are increasingly integrated into healthcare, the ability to navigate them correctly and efficiently is important. Studies have shown that higher eHL is associated with better medication adherence and health behaviors in elderly patients with heart failure and college students [19, 20]. Meanwhile, those with limited eHL may struggle to use digital inhalers, understand information regarding triggers and medications, and translate this information into actions, potentially reducing the effectiveness of digital inhalers. Consequently, health disparities can be widened by digital health interventions [21] that are not sufficiently usable for populations with lower eHL levels.

Although previous studies have shown that digital inhalers can improve medication adherence and reduce inhaler use errors, their effectiveness had been demonstrated only on the short term [7-9, 22]. The recent ACCEPTANCE study, a 12-month randomized controlled trial, showed that a digital inhaler program significantly improved medication adherence over 6 months and asthma control over 12 months [23]. Subgroup analyses using estimated marginal means showed these effects were not significantly modified by attitude towards the program, self-efficacy, and medication beliefs [23]. However, moderation effects of illness perception and eHL remain unknown. Examining this can help identify patients who may benefit most from the digital inhaler program and those who may require additional support, thereby informing more tailored and equitable implementation strategies, and guiding the development of support measures to maximize benefits for all asthma patients. While fixed characteristics such as age and gender might also affect effectiveness, illness perceptions and eHL are modifiable and can shape how individuals engage with digital inhalers more directly.

The current study aims to examine potential moderation effects of asthma patients' illness perceptions and eHL on the effectiveness of a digital inhaler program in terms of medication adherence and asthma control. For exploratory analyses, we also aim to explore whether demographic characteristics are associated with illness perceptions and eHL levels in Dutch primary care settings. Specifically, we intend to answer the following research questions (RQs):

1) Do illness perceptions and eHL moderate the effectiveness of a digital inhaler program in terms of medication adherence and asthma control?
2) To what extent are sociodemographic characteristics associated with illness perceptions and eHL?

Methods

Study design

This is a post-hoc analysis of the 12-month cluster randomized controlled ACCEPTANCE trial conducted in primary care practices in the Netherlands from November 2019 to June 2023. This two-arm trial with an intervention and control arm (164 participants in total, with 82 in each arm) included an initiation visit (T-1), 6-week run-in period (week -2) for intervention and survey data collection at baseline (T0, week 0), and at 3 (T3, week 12), 6 (T6, week 26), 9 (T9, week 40), 12 months (T12, week 52) from baseline. As a part of the ACCEPTANCE study, the protocol, procedure details and primary results were published previously [23, 24]. Ethical approval was acquired

from The Medical Research Ethics Committee of Assen, the Netherlands (NL69909.056.19).

Participants

Patients with diagnosed asthma were recruited from general practices and pharmacies through electronic medical record screening or from social media. Patients recruited from the same general practices were considered as a single cluster while each individual from pharmacies or social media was treated as a separate cluster. Participants were included if they: 1) were aged 18 years or older with uncontrolled asthma (Asthma Control Questionnaire-5 [ACQ-5] score of ≥0.75) as they were more likely to benefit from the intervention; 2) had a smartphone; 3) used budesonide/formoterol SYMBICORT Turbuhaler (AstraZeneca, the Hague, the Netherlands) as maintenance therapy for 8 weeks or longer; and 4) took medications as prescribed for fewer than 80% of adherent days at week 3-4 during a 6-week run-in period. This is the most commonly used adherence cutoff in adherence research, and ensured the inclusion of patients with suboptimal adherence and provided a more stable estimate of habitual medication use, while still allowing sufficient time to determine eligibility and complete study procedures before randomization.

Participants were excluded if they: 1) used a budesonide/formoterol SYMBICORT Turbuhaler as maintenance and reliever therapy; 2) used systemic corticosteroids or had to change prescribed inhaled corticosteroid doses in the 4 weeks before the run-in period; 3) used asthma biologics; 4) had chronic obstructive pulmonary disease or other severe respiratory conditions, a life expectancy of <1 year, or were pregnant and unable to understand Dutch. The initial sample size calculation was based on detecting a 15% absolute difference in mean medication adherence with 90% power and a two-sided 5% significance level. Given unexpected recruitment challenges due to the COVID-19 pandemic, the sample size was calculated in different scenarios based on a power of 80% and varying drop-out rates [24]. In the end, 81 patients per arm were considered sufficient to have a power of 80% with 16% expected dropout [23, 24].

Randomization and masking

Patients recruited from the same general practices were considered as a single cluster while each individual from pharmacies or social media was treated as a separate cluster. A 1:1 cluster-level randomization was applied to patients to enter the intervention or control group. Stratified by practice size (≤2500 patients or >2500 patients, determined by the recent practice size in the Netherlands), a computer-generated permuted block scheme was used with random block sizes of 4 and 6. Randomization took place after the first patient of a general practitioner finished the run-in period, and practice staff

were then notified of allocation. No more patients from the same general practice entered into the run-in period to minimize recruitment bias. Patients from pharmacies and social media were randomized similarly. Due to the study design, patients and outcome assessors were not blinded to allocation. Data analysts were masked to group allocation.

Procedures

Eligible patients were approached with an invitation letter and a reply envelope. A detailed overview of measurements at different timepoints can be seen in the protocol [24]. Sociodemographics, asthma control and asthma medication use were collected during a remote screening visit (T-1). Afterwards, participants completed a 6-week run-in period, attaching an electronic monitoring device (EMD) to the SYMBICORT Turbuhaler. Logging date and time of inhaler actuations were recorded in the EMD. After a final eligibility confirmation (see Participants), baseline data were collected at T0 and participants were informed of the allocation. Medication adherence was monitored continuously. Follow-up data on asthma control were collected at T3, T6, T9, T12. Data were originally collected during home-visits to enhance the data validity but due to COVID-19 social distancing restrictions, data were collected remotely at T0, T6 and T12. There were no differences in home visits and remote procedure (by videocall) as the measures were the same.

Interventions

The digital inhaler program was designed to improve unintentional nonadherence, such as forgetting to take prescribed medications, by sending reminders, providing adherence monitoring data and feedback on inhaler use. Participants and HCPs received instructions face to face or by remote training on how to use the EMD and the application, but not on the interaction with the program, to mimic a real-world situation. Participants in the intervention group (digital inhaler program) used the EMD Turbu+ device (medical device class I, manufactured by Adherium (NZ), CE marked) connected to their inhalers. They installed the Turbu+ Insights application on their smartphones at T0, with assistance provided for less digitally literate patients. The real-time actuation data logged by the EMD were sent to the application automatically via Bluetooth when the smartphone was within a 5-meter range. If it was out of range, data could be stored on the device and was sent to the application when it was within range. Data could also be uploaded manually.

The functions of Turbu+ Insights included visualization of inhaler use, reminders, missed dose and overuse messages, motivational messages, and a symptoms and

triggers tracker. These components may support their habit formation, increase self-monitoring, awareness of adherence behavior and their motivations and engagement in self-management. Patients' HCPs could access the inhaler use data in the online Turbu+ portal. Patients could view their inhaler use data, record their triggers and symptoms, and receive reminders on the app while their HCPs could set and adjust the medication regimen in the portal. Participants in the control group (passive electronic monitoring) attached the EMD that was connected to another application Hailie Lite, in which inhalation use was passively and automatically monitored without any feedback and reminders, and patients and HCPs were not able to view their inhaler data. Data were only visible for the research team. HCPs in both groups were informed to follow usual care guidelines. More details can be seen in the original study [23].

Measures

Main outcomes

Medication adherence was measured by electronic monitoring of inhaler actuations to track real-time objective data. To evaluate the intervention effects over time in the original study, it was calculated as the number of recorded inhalations divided by the number of inhalations prescribed per day, corrected for dose dumping (≥6 actuations within a 5 minute period), ranging from 0-100%. For data analysis, it was recoded into weekly adherence (in-study definition), the means of daily adherence rate that week. To avoid white coat adherence effects [25], medication adherence data a week before and a week after visits were disregarded during selection. Due to technological issues, some data were missing and the number of days for which data were available for each participant during that week was also recorded. Detailed information about tackling potential bias, Hawthorne effect and white coat adherence were described in the protocol [24].

Asthma control was measured with the validated 5-item Asthma Control Questionnaire [26] (ACQ), assessing patients' sleep deprivation, symptoms on waking, activity impairment, dyspnea and wheezing respectively during the previous week. Each item was scored from 0 to 6, with answer categories ranging from "totally controlled" to "extremely poorly controlled". The ACQ score was calculated as the mean of five items. Patients with a mean score of ≤0.75 were considered as having controlled asthma and higher scores indicated more uncontrolled asthma [27].

Moderator variables

Illness perception was measured with the validated brief Illness Perception Questionnaire (B-IPQ) [14] (Dutch version) for asthma. This scale measures patients' perceptions of the illness' *consequence*, *timeline*, *personal control*, *treatment, identity*,

concern, *understanding*, *emotion* with 8 items. Each item was scored from 0-10. Item 9 is an open-ended question about causes of asthma. When calculating the total IPQ scores (from 0 to 80), we reversed item 3, 4 and 7 to interpret higher IPQ scores as more negative illness perceptions, with item 9 excluded.

eHealth literacy was measured with the validated Dutch version of the eHealth Literacy Questionnaire (eHLQ) [28]. This 35-item scale assesses seven domains rated on a 5-point Likert scale from 1=strongly disagree to 5=strongly agree: *ability to process information*, *engagement in own health*, *ability to actively engage with digital services*, *feel safe and in control, motivated to engage with digital services*, *access to digital services that work*, *digital services that suit individual needs*. The total eHLQ scores were calculated by adding all items, ranging from 35-175, with higher scores indicating higher eHealth literacy.

Given the exploratory nature of this post-hoc analysis and the limited sample size, examining each dimension separately was beyond the scope of the current study and could have resulted in unstable estimates. Therefore, in this study, we used the overall B-IPQ and eHLQ scores to reflect participants' general illness perceptions and eHL.

Participant characteristics

Sociodemographic characteristics were collected including age in years, sex (male/female), educational level (low = no education/primary school/lower general or vocational education/intermediate general secondary education; medium = higher general secondary education and pre-university education/intermediate vocational education; high = higher professional education/university).

Statistical analyses

Descriptive statistics were presented as means (M) and standard deviations (SD), medians and interquartile ranges (IQR), or frequencies and percentages depending on measurement levels and distributions of variables. For each outcome in RQ1, two mixed-effects models were performed in R 4.5.1 [29] with the lme4 package [30]: a main-effects model (model 1), and a moderation model (model 2). First, model 1 was conducted by entering mean medication adherence at week 2-26 as the dependent variable, study arm (intervention/control group) as the independent variable, and week (2-26), age, sex and educational level as covariates to control for differences in baseline characteristics. Model 2 was estimated similarly including the interaction term (study arm * B-IPQ). The number of days with adherence data was entered into the model as a weighting factor to ensure better model accuracy and reliability. This is because observations derived from a larger number of monitored days were considered to

provide more precise estimates of adherence and were therefore given greater weight in the analyses. Imputation was not applied as data were not missing at random. Second, ACQ scores from T0 to T6 were listed as the dependent variable in model 1, study arm (intervention/control group) as the independent variable, time (T0/T3/T6), age, sex and educational level as covariates. The interaction term (study arm * B-IPQ) was included in model 2. A sensitivity analysis was conducted using ACQ scores at T12 instead of T3 and T6, as the effect of the digital inhaler program on asthma control was significant at 12 months [23].

Similar moderation analyses were performed by using eHL as the moderator variable, adding the interaction term study arm * eHLQ. B-IPQ and eHLQ scores were mean centered prior to moderation analyses.

For RQ2, two multivariable linear regression models were performed with sociodemographic characteristics (age, sex and educational level) as independent variables, and B-IPQ and eHL scores as dependent variables in the two models, respectively. A $p<0.05$ was considered statistically significant. We ensured all assumptions were met prior to regression analyses, including normal distribution, homoscedasticity and multicollinearity.

Results

Baseline characteristics

A total of 164 patients with uncontrolled asthma were included in this study, with a mean age of 47.7 years (SD 15.2). Among them, 68 (41.5%) were male and 73 (44.5%) had a high educational level. Patients at baseline had relatively high medication adherence with substantial variability, with a median of 85.7% (IQR 38.4%). The baseline median ACQ score was 1.6 (IQR 1.0), suggesting uncontrolled asthma with moderate variability. Participants had a mean score of 35.0 (SD 8.2) on the B-IPQ and 100.3 (SD 13.5) on the eHLQ, indicating relatively positive perceptions of asthma and a medium level of eHL. A detailed description is presented in Table 1.

Table 1 Baseline characteristics of patients

Categories	Overall (n=164)	Control (n=82)	Intervention (n=82)
Age in years (M, SD)	47.7, 15.2	47.0, 15.6	48.3, 15.0
Male sex (n, %)	68, 41.5	36, 43.9	32, 39.0
Educational level, (n, %)			
Low	30 (18.3)	13 (15.9)	17 (20.7)
Medium	61 (37.2)	36 (43.9)	25 (30.5)
High	73 (44.5)	33 (40.2)	40 (48.8)
Medication adherence during week 3 and 4 of run-in period (%) (median, IQR)[a]	42.9 (14.3-71.4)	50.0 (21.4-71.4)	42.9 (14.3-64.3)
Medication adherence during week 3 and 4 of run-in period, in-study definition (%) (M, SD)[b]	64.0 (24.8)	65.4 (25.0)	62.6 (24.8)
ACQ[c] scores (median, IQR)	1.6, 1.0	1.6, 1.0	1.6, 1.0
B-IPQ[d] scores (M, SD) (n=154)	35.0, 8.2	35.6, 8.1	34.5, 8.3
eHLQ[e] scores (M, SD) (n=154)	100.3, 13.5	102.0, 14.9	98.6, 12.0

a: Adherent days per total number of days (ie, a nonadherent day is considered a day when taking not all prescribed inhalations).

b: Daily inhalations taken per daily inhalations prescribed.

c: Asthma Control Questionnaire.

d: brief Illness Perception Questionnaire.

e: eHealth Literacy Questionnaire.

Modeling role of illness perceptions and eHL on medication adherence and asthma control (RQ1)

After adding an interaction term, the moderation models (model 2) revealed that neither B-IPQ nor eHLQ scores had moderation effects on medication adherence or ACQ scores (p>0.05) (Table 2). In other words, illness perceptions and eHL did not modify the effectiveness of the digital inhaler program on medication adherence and asthma control. However, in the main effects, higher eHLQ scores were associated with slightly lower medication adherence (b=-0.01, p<0.05), and higher B-IPQ scores were associated with higher ACQ scores (b=0.03, p<0.05) or poorer asthma control (Table 2). Sensitivity analysis confirmed that even though the digital inhaler had a positive impact on reducing ACQ scores over 12 months, B-IPQ or eHLQ scores had no moderation effects at 12 months (p>0.05), see details in Supplementary Materials.

Table 2 Moderation analyses of illness perceptions and eHealth literacy on medication adherence and asthma control

Predictors	Medication adherence (week 2-26)				Asthma control (T0-T6)			
	Illness perceptions as moderator		eHL as moderator		Illness perceptions as moderator		eHL as moderator	
	Model 1	Model 2	Model 1	Model 2	Model 1	Model 2	Model 1	Model 2
Study arm (intervention vs. control)	0.08	0.08	0.06	0.06	-0.17	-0.17	-0.22*	-0.22*
B-IPQ[a]	-0.00	0.00			0.03*	0.04*		
eHLQ[a]			-0.01*	-0.01*			-0.00	-0.00
Time (in weeks)	-0.00*	-0.00*	-0.00*	-0.00*				
Time (T3 vs. T0)					-0.17*	-0.17*	-0.17*	-0.17*
Time (T6 vs. T0)					-0.28*	-0.28*	-0.28*	-0.28*
Age	0.00*	0.00*	0.00	0.00	0.00	0.00	-0.00	0.00
Gender (male vs. female)	0.07	0.07	0.08	0.08	-0.21*	-0.21*	-0.22*	-0.22
Educational level (middle vs. low)	0.09	0.09	0.11	0.11	-0.15	-0.13	-0.26	-0.26
Educational level (high vs. low)	0.12	0.13*	0.15*	0.16*	-0.02	-0.01	-0.11	-0.11
Study arm * B-IPQ		-0.01				-0.01		
Study arm * eHLQ				0.00				-0.00

Note: numbers in the table are *b*s.

a: centered value.

*: $p<0.05$.

Associations between demographics and illness perceptions and eHL (RQ2)

The multivariable linear regression results (Table 3) showed that age was negatively associated with eHLQ scores (b=-0.3, p<0.01), such that higher age was related to lower eHL. Other demographic characteristics were not significantly associated with illness perceptions or eHL (p>0.05). Details can be found in Table 3.

Table 3 Multivariable linear regression results for illness perceptions and eHealth literacy

Predictors	Categories	Regression for B-IPQ[a] scores		Regression for eHLQ[b] scores	
		b (95% CI)	*p*	*b* (95% CI)	*p*
Age in years		0.0 (-0.1, 0.1)	.63	-0.3 (-0.4, -0.1)	<.01*
Sex	Female	Reference		Reference	
	Male	0.5 (-2.3, 3.3)	.74	2.4 (-2.0, 6.8)	.28
Educational level	Low	Reference		Reference	
	Medium	-2.9 (-6.7, 0.9)	.13	3.3 (-2.6, 9.2)	.27
	High	-2.8 (-6.5, 1.0)	.15	4.7 (-1.2, 10.6)	.12

a: Brief Illness Perception Questionnaire.

b: eHealth Literacy Questionnaire.

*: p<0.05.

Discussion

Building on the ACCEPTANCE trial, which showed that a digital inhaler program improved medication adherence for 6 months and asthma control for 12 months, this post-hoc analysis provides insights into individual-level factors that might moderate intervention outcomes. To our knowledge, no intervention studies examined whether illness perceptions and eHL moderated the effectiveness of digital inhalers, or more broadly, of eHealth interventions for asthma. The current study showed that illness perceptions and eHL did not modify the program's effectiveness. However, younger age was significantly associated with higher eHL. No other significant associations were found between demographics and B-IPQ or eHL.

Previous studies have shown that positive illness perceptions and higher eHL are associated with better health behaviors and outcomes in asthma patients and elderly people [15, 16, 31], such as physical activities and asthma control, although they did not focus on interventions. However, our study found no moderating effect of illness perceptions and eHL on the digital inhaler program's impact on medication adherence

or asthma control. This suggests that the program is equally effective across different levels of illness perceptions and eHL, potentially due to the intervention design. Several explanations can be considered. First, the digital inhaler program actively provided reminders and feedback, which likely had a stronger influence on medication adherence and asthma control than patients' illness perceptions or eHL levels. Second, the program demonstrated good usability and acceptability [23] such that it requires minimal digital skills to navigate, as patients were basically passive recipients with instructions provided during installation and implementation [24]. These features may have resulted in the program producing relatively uniform benefits across participants. However, an alternative explanation is that our patients had overall positive illness perceptions of asthma and a moderate level of eHL at baseline, indicating a good understanding of their conditions and sufficient capability to engage with this program.

Younger patients tended to have higher eHL in our study. This aligns with eHL studies conducted in Korean adults [32] and older adults with cancer in Puerto Rico [33], and our previous survey among Chinese general population [34]. Higher eHL among younger participants may be attributed to their greater exposure to digital technologies and online health resources, as well as their higher proficiency in using these tools [35] or higher educational levels. This association between age and eHL may partly reflect the global digital divide, the gap between people who have access to information communication technology (ICT) and those who do not [36], thereby contributing to health disparity. This divide is driven by factors such as poverty, low literacy, lack of access to ICT, or lack of interest or motivation to use ICT, and is particularly evident in the elderly, ethnic and gender minorities, individuals with low socioeconomic positions and rural areas [34, 37]. With the digitalization of healthcare globally, individuals with lower eHL or limited digital access may be unable to fully benefit from digital health. This underscores the need for future eHealth interventions to be designed in a more accessible and inclusive manner.

Our findings have several implications and recommendations for similar digital inhaler programs or eHealth interventions. The program is effective regardless of patients' illness perceptions and eHL levels, highlighting the intervention should work well across diverse patients. The user-friendly design and easy access to the program may have played an important role in its effectiveness, and should be prioritized during future development of digital inhalers to ensure good usability and acceptability. Involving a diverse and inclusive group of end-users in the development and evaluation process is also considered important [38]. To prevent widening the digital divide, especially for those with lower eHL, it is recommended to follow an inclusive eHealth guide and tailor interventions to meet their specific needs and preferences, such as using

visual elements, shorter and separate pages, and providing informal, up-to-date and credible information [39]. In addition, providing digital health support can help them make better use of eHealth interventions. For example, among elderly people, offering family-based guidance and promoting their greater practical engagement in internet have proved to be useful in improving their eHL [40]. Future research can consider promoting the digital inhaler program to non-Dutch speaking populations, who might have worse health outcomes and make less efficient use of Dutch health care. Furthermore, intervention elements, mechanisms and additional insights into users' experiences from qualitative methods should be considered in future eHealth evaluation studies to better understand how to make them effective and equitable across diverse populations. As different dimensions of illness perceptions and eHL may influence intervention effects, future research with larger sample size can also examine the moderating effects of separate domains of the B-IPQ and eHLQ rather than relying solely on the composite score.

This study has several strengths. First, this is the first study incorporating illness perceptions and eHL as potential moderators, which have been underexplored in previous digital inhaler studies and eHealth intervention studies. Second, the 12-month follow-up and implementation in the primary care setting offered real-world insights that can inform clinical practice for asthma care, especially for suboptimally controlled and non-adherent asthma patients. However, some limitations should be acknowledged. With this being a post-hoc analysis, the trial was not originally designed to explore moderation. Reliance on self-reported measures for illness perceptions and eHL may introduce reporting bias. Furthermore, results should be extrapolated with caution due to the small sample size, additional weighting in the mixed-effects model, specific patients involved with suboptimally controlled asthma, and the use of a specific type of digital inhaler characterized by a user-friendly design, good acceptability and usability.

Conclusion

The digital inhaler program improved medication adherence for 6 months and asthma control for 12 months for non-adherent asthma patients regardless of their illness perceptions and eHealth literacy levels. Younger patients demonstrated greater eHealth literacy. Future studies should look into intervention elements, mechanisms and gain qualitative insights into users' experiences to make eHealth interventions effective and equitable across diverse population. Meanwhile, accessibility, good acceptability, usability and ensuring inclusiveness during development of digital inhalers should be prioritized.

Abbreviations

ACQ: Asthma Control Questionnaire.
B-IPQ: the Brief Illness Perception Questionnaire.
eHLQ: eHealth Literacy Questionnaire.
EMD: electronic monitoring device.
RQ: research question.

Chapter 6

Supplementary material

Moderation analyses of illness perceptions and eHealth literacy on asthma control

Predictors	Asthma control (T0-T12)			
	Illness perceptions as moderator		eHL as moderator	
	Model 1	Model 2	Model 1	Model 2
Study arm (intervention vs. control)	-0.20*	-0.20*	-0.24*	-0.24*
B-IPQ[a]	0.03*	0.04*		
eHLQ[a]			-0.00	-0.00
Time (T3 vs. T0)	-0.16*	-0.16*	-0.16*	-0.16*
Time (T6 vs. T0)	-0.28*	-0.28*	-0.28*	-0.28*
Time (T9 vs. T0)	-0.22*	-0.22*	-0.22*	-0.22*
Time (T12 vs. T0)	-0.23*	-0.23*	-0.23*	-0.23*
Age	0.00	0.00	-0.00	0.00
Gender (male vs. female)	-0.23*	-0.23*	-0.24*	-0.24*
Educational level (middle vs. low)	-0.15	-0.13	-0.26	-0.26
Educational level (high vs. low)	-0.06	-0.05	-0.14	-0.14
Study arm * B-IPQ		-0.01		
Study arm * eHLQ				-0.00

Note: numbers in the table are *b*s.

a: centered value.

*: $p<0.05$.

References

1. Mims JW: Asthma: definitions and pathophysiology. Int Forum Allergy Rhinol 2015, 5 Suppl 1:S2-6. [doi: 10.1002/alr.21609].

2. Asthma [https://www.who.int/news-room/fact-sheets/detail/asthma]

3. Jansen EM, van de Hei SJ, Dierick BJH, Kerstjens HAM, Kocks JWH, van Boven JFM. Global burden of medication non-adherence in chronic obstructive pulmonary disease (COPD) and asthma: a narrative review of the clinical and economic case for smart inhalers. J Thorac Dis 2021, 13(6):3846-3864. [doi: 10.21037/jtd-20-2360].

4. Chan A, De Simoni A, Wileman V, Holliday L, Newby CJ, Chisari C, Ali S, Zhu N, Padakanti P, Pinprachanan V *et al*: Digital interventions to improve adherence to maintenance medication in asthma. Cochrane Database Syst Rev 2022, 6(6):CD013030. [doi: 10.1002/14651858.CD013030.pub2].

5. Engelkes M, Janssens HM, de Jongste JC, Sturkenboom MC, Verhamme KM: Medication adherence and the risk of severe asthma exacerbations: a systematic review. Eur Respir J 2015, 45(2):396-407. [doi: 10.1183/09031936.00075614].

6. Chan AHY, Pleasants RA, Dhand R, Tilley SL, Schworer SA, Costello RW, Merchant R: Digital Inhalers for Asthma or Chronic Obstructive Pulmonary Disease: A Scientific Perspective. Pulm Ther 2021, 7(2):345-376. [doi: 10.1007/s41030-021-00167-4].

7. Chan AH, Stewart AW, Harrison J, Camargo CA, Jr., Black PN, Mitchell EA: The effect of an electronic monitoring device with audiovisual reminder function on adherence to inhaled corticosteroids and school attendance in children with asthma: a randomised controlled trial. The Lancet Respiratory medicine 2015, 3(3):210-219. [doi: 10.1016/S2213-2600(15)00008-9].

8. Foster JM, Usherwood T, Smith L, Sawyer SM, Xuan W, Rand CS, Reddel HK: Inhaler reminders improve adherence with controller treatment in primary care patients with asthma. The Journal of allergy and clinical immunology 2014, 134(6):1260-1268 e1263. [doi: 10.1016/j.jaci.2014.05.041].

9. Moore A, Preece A, Sharma R, Heaney LG, Costello RW, Wise RA, Ludwig-Sengpiel A, Mosnaim G, Rees J, Tomlinson R *et al*: A randomised controlled trial of the effect of a connected inhaler system on medication adherence in uncontrolled asthmatic patients. Eur Respir J 2021, 57(6). [doi: 10.1183/13993003.03103-2020].

10. A Brief Introduction to the COM-B Model of Behaviour and the PRIME Theory of Motivation [https://www.qeios.com/read/WW04E6.3]

11. Munns A, Wiffen L, Brown T, Fasulo A, Chauhan M, D'Cruz L, Kaklamanou D, Chauhan AJ: Capability, Opportunity, and Motivation Model for Behavior Change in People With Asthma: Protocol for a Cross-Sectional Study. JMIR research protocols 2023, 12:e44710. [doi: 10.2196/44710].

12. Steed L, Sheringham J, McClatchey K, Hammersley V, Marsh V, Morgan N, Jackson

T, Holmes S, Taylor S, Pinnock H: IMP(2)ART: development of a multi-level programme theory integrating the COM-B model and the iPARIHS framework, to enhance implementation of supported self-management of asthma in primary care. Implement Sci Commun 2023, 4(1):136. [doi: 10.1186/s43058-023-00515-2].

13. Zhang J, Hu J, Zheng Y, Dai T: Factors affecting medication adherence in patients with chronic diseases: A systematic literature review. Chinese General Practice Journal 2025, 2(3):100072. [doi: https://doi.org/10.1016/j.cgpj.2025.100072].

14. Broadbent E, Petrie KJ, Main J, Weinman J: The brief illness perception questionnaire. J Psychosom Res 2006, 60(6):631-637. [doi: 10.1016/j.jpsychores.2005.10.020].

15. Silva STC, Freitas PD, Lunardi AC, Xavier RF, Barbosa RCC, Stelmach R, Carvalho CRF: Association between illness perception and clinical control, quality of life, physical activity, and psychosocial status in subjects with moderate to severe asthma: a cluster analysis. J Asthma 2023, 60(1):115-122. [doi: 10.1080/02770903.2022.2032136].

16. Cai Q, Jin M, Li X, Zhang J, Xu Q, Ye L, Lyu Q: Effect of illness perceptions on asthma control and quality of life amongst adult outpatients with asthma in China. BMC Psychol 2023, 11(1):68. [doi: 10.1186/s40359-023-01097-3].

17. Eshete A, Getye B, Aynaddis G, Tilaye B, Mekonnen E, Taye B, Zeleke D, Deresse T, Kifleyohans T, Assefa Y: Association between illness perception and medication adherence in patients with diabetes mellitus in North Shoa, Zone: cross-sectional study. Frontiers in public health 2023, 11:1214725. [doi: 10.3389/fpubh.2023.1214725].

18. Norman CD, Skinner HA: eHealth Literacy: Essential Skills for Consumer Health in a Networked World. J Med Internet Res 2006, 8(2):e9. [doi: 10.2196/jmir.8.2.e9].

19. Lin CY, Ganji M, Griffiths MD, Bravell ME, Brostrom A, Pakpour AH: Mediated effects of insomnia, psychological distress and medication adherence in the association of eHealth literacy and cardiac events among Iranian older patients with heart failure: a longitudinal study. Eur J Cardiovasc Nurs 2020, 19(2):155-164. [doi: 10.1177/1474515119873648].

20. Hsu W, Chiang C, Yang S: The effect of individual factors on health behaviors among college students: the mediating effects of eHealth literacy. J Med Internet Res 2014, 16(12):e287. [doi: 10.2196/jmir.3542].

21. Konig LM, Krukowski RA, Kuntsche E, Busse H, Gumbert L, Gemesi K, Neter E, Mohamed NF, Ross KM, John-Akinola YO *et al*: Reducing intervention- and research-induced inequalities to tackle the digital divide in health promotion. Int J Equity Health 2023, 22(1):249. [doi: 10.1186/s12939-023-02055-6].

22. Dierick BJH, Achterbosch M, Eikholt AA, Been-Buck S, Klemmeier T, van de Hei SJ, Hagedoorn P, Kerstjens HAM, Kocks JWH, van Boven JFM: Electronic monitoring with a digital smart spacer to support personalized inhaler use education in patients

with asthma: The randomized controlled OUTERSPACE trial. Respir Med 2023, 218:107376. [doi: 10.1016/j.rmed.2023.107376].

23. van de Hei SJ, van den Berg LN, Poot CC, Gerritsma YH, Meijer E, Flokstra-de Blok BMJ, Postma MJ, van Boven JFM, Chavannes NH, Kocks JWH: Long-Term Effectiveness of a Digital Inhaler on Medication Adherence and Clinical Outcomes in Adult Asthma Patients in Primary Care: The Cluster Randomized Controlled ACCEPTANCE Trial. J Allergy Clinical Immunol Pract 2025, 13(7):1693-1704. [doi: 10.1016/j.jaip.2025.03.013].

24. van de Hei SJ, Poot CC, van den Berg LN, Meijer E, van Boven JFM, Flokstra-de Blok BMJ, Postma MJ, Chavannes NH, Kocks JWH: Effectiveness, usability and acceptability of a smart inhaler programme in patients with asthma: protocol of the multicentre, pragmatic, open-label, cluster randomised controlled ACCEPTANCE trial. BMJ Open Respir Res 2022, 9(1). [doi: 10.1136/bmjresp-2022-001400].

25. Poleon S, Sabbagh N, Racette L: Whitecoat Adherence in Patients With Primary Open-Angle Glaucoma. Front Med (Lausanne) 2022, 9:867884. [doi: 10.3389/fmed.2022.867884].

26. Juniper EF, O'Byrne PM, Guyatt GH, Ferrie PJ, King DR: Development and validation of a questionnaire to measure asthma control. Eur Respir J 1999, 14(4):902-907. [doi: 10.1034/j.1399-3003.1999.14d29.x].

27. Juniper EF, Bousquet J, Abetz L, Bateman ED, Committee G: Identifying 'well-controlled' and 'not well-controlled' asthma using the Asthma Control Questionnaire. Respir Med 2006, 100(4):616-621. [doi: 10.1016/j.rmed.2005.08.012].

28. Poot CC, Meijer E, Fokkema M, Chavannes NH, Osborne RH, Kayser L: Translation, cultural adaptation and validity assessment of the Dutch version of the eHealth Literacy Questionnaire: a mixed-method approach. BMC Public Health 2023, 23(1):1006. [doi: 10.1186/s12889-023-15869-4].

29. R: A Language and Environment for Statistical Computing [https://www.R-project.org/]

30. Bates D, Maechler M, Bolker B, Walker S, Christensen RHB, Singmann H, Dai B, Grothendieck G, Green P, Bolker MBJc: Package ‘lme4’. 2015, 12(1):2. [doi.

31. Cui GH, Li SJ, Yin YT, Chen LJ, Li JQ, Liang FY, Liu XY, Chen L: The relationship among social capital, eHealth literacy and health behaviours in Chinese elderly people: a cross-sectional study. BMC Public Health 2021, 21(1):45. [doi: 10.1186/s12889-020-10037-4].

32. Park SY, Chung S: E-health literacy and associated factors among Korean adults during the COVID-19 pandemic: age-group differences. Health Promot Int 2023, 38(5). [doi: 10.1093/heapro/daad099].

33. Hoogland AI, Mansfield J, Lafranchise EA, Bulls HW, Johnstone PA, Jim HSL: eHealth literacy in older adults with cancer. J Geriatr Oncol 2020, 11(6):1020-1022. [doi: 10.1016/j.jgo.2019.12.015].

34. Sun C, Meijer E, Chavannes NH, Dai H, Li X, Wang Y, Wu L, Zhang Q, Kasteleyn MJ: eHealth literacy in the general population: a cross-sectional study in China. BMC Public Health 2025, 25(1):211. [doi: 10.1186/s12889-025-21389-0].

35. Stellefson M, Hanik B, Chaney B, Chaney D, Tennant B, Chavarria EA: eHealth literacy among college students: a systematic review with implications for eHealth education. J Med Internet Res 2011, 13(4):e102. [doi: 10.2196/jmir.1703].

36. Lythreatis S, Singh SK, El-Kassar A-NJTF, Change S: The digital divide: A review and future research agenda. 2022, 175:121359. [doi.

37. Saeed SA, Masters RM: Disparities in Health Care and the Digital Divide. Curr Psychiatry Rep 2021, 23(9):61. [doi: 10.1007/s11920-021-01274-4].

38. van Vliet MHM, van Eersel RA, Poot CC, Faber JS, Aardoom JJ, Meijer E, Versluis A: A practical step-by-step approach for patient and public involvement in eHealth intervention research: Lessons learned from three case projects. Internet Interventions 2025:100896. [doi: https://doi.org/10.1016/j.invent.2025.100896].

39. Faber JS, Al-Dhahir I, Kraal JJ, Breeman LD, van den Berg-Emons RJG, Reijnders T, van Dijk S, Janssen VR, Kraaijenhagen RA, Visch VT *et al*: Guide Development for eHealth Interventions Targeting People With a Low Socioeconomic Position: Participatory Design Approach. J Med Internet Res 2023, 25:e48461. [doi: 10.2196/48461].

40. Wu J, Peng H: Family guidance regarding internet mitigates older adults' ehealth literacy inequality due to educational attainment through internet use. Geriatr Nurs 2025, 61:414-422. [doi: 10.1016/j.gerinurse.2024.12.002].

Chapter 7

General discussion

7.1 Overview of main findings

This thesis aimed to enhance understanding of health education needs and behavioral challenges regarding chronic lung disease (CLD), and to examine the potential of eHealth in supporting CLD health education and behavior change from a global perspective. Specifically, it aimed to: 1) explore beliefs, perceptions and behaviors related to CLD; 2) assess eHealth literacy (eHL) and its determinants; 3) evaluate the potential of eHealth for CLD health education and behavior change. Drawing on evidence from three different countries, three key findings emerged:

1) *Beliefs, perceptions and behaviors:* Misperceptions and misbeliefs about CLD and its causes were identified among community members (CMs) and healthcare professionals (HCPs) in Kyrgyzstan, along with several behavioral challenges. CMs had a high prevalence of smoking, used biomass and fossil fuels for cooking and heating, which are considered as risk factors of CLD, and delayed help-seeking (e.g., resorting to traditional medicine and self-medication rather than seeking timely care from HCPs). HCPs provided restricted and experience-based helping behaviors (e.g., referring patients to better-equipped facilities, using antibiotics and rarely using guidelines), instead of delivering sufficient and evidence-based care with adequate medical resources and adhering to guidelines.
2) *eHL and knowledge:* Our sample drawn from the general population in China showed limited eHL and CLD-related knowledge, with higher eHL being associated with younger age, higher education and income level, more digital access, frequent eHealth use, and more positive attitudes towards eHealth.
3) *eHealth potential:* eHealth studies for CLD health education have been primarily conducted in high-income countries (HICs), and have reported positive effects on awareness, clinical, psychosocial, lifestyle and cost-effectiveness outcomes, with good feasibility, acceptability and user satisfaction. Furthermore, a digital inhaler program demonstrated effectiveness on improving asthma control and medication adherence for asthma in Dutch primary care. The program seemed effective regardless of patients' eHL and illness perceptions, possibly due to the user-friendly design, sample selection and high baseline eHL.

7.2 Interpretations and recommendations

7.2.1 Knowledge gap in CLD and implications for tailored health education

This thesis provided new insights into context-specific content and patterns of misbeliefs and misperceptions about CLD (**Chapter 2** and **Chapter 3**) in CMs and HCPs in Kyrgyzstan, as well as limited CLD-related knowledge (**Chapter 4**) among

the Chinese general population, indicating a knowledge gap in CLD. This is consistent with previous research in low- and middle-income countries (LMICs) showing low awareness of CLD in general populations [1, 2], patients [3, 4] and HCPs [1, 2, 4]. In **Chapter 2** and **Chapter 3**, CMs and HCPs commonly misperceived typical CLD conditions as acute illnesses such as colds or infectious diseases, rather than chronic diseases, and attributed them to cold weather. In **Chapter 4**, however, while the Chinese general population demonstrated low CLD-related knowledge scores, many of them considered medical (e.g., poor medical care in the past, a germ or virus) or lifestyle factors (e.g., smoking, diet or eating habits) rather than weather as potential causes. By comparing distinct settings, these findings indicate that, beyond the overall low awareness of CLD, understanding of the condition does vary in different contexts. These variations may be explained by the slow progression of CLD [4], the normalization of smoking, cough and weather [2, 5], limited literacy or lack of diagnostic tools [2, 5], all of which are embedded within broader cultural, geographic and socioeconomic contexts.

Therefore, health education should be culturally tailored to reflect local contexts and needs, explicitly addressing locally embedded beliefs and perceptions, while also strengthening basic disease recognition and risk awareness. For example, in the Kyrgyz settings where CLD symptoms are commonly interpreted as colds or attributed to cold weather, educational content should be tailored to their knowledge level to directly clarify the chronic and progressive nature of CLD and its causal relationships with long-term exposures to smoking and air pollution [6]. Our findings also suggest that appropriate delivery mediums or formats are important considerations in the design of health education, such as widely used web-based platforms, and mobile applications or tablets (**Chapter 5**), which can enhance accessibility and user engagement. Beyond delivery formats, evidence from low-resource settings highlighted the importance of community-based approaches that engage local stakeholders and co-create locally adapted materials, which have been shown to be feasible, acceptable, and effective in improving awareness of smoking and household air pollution (HAP) [7]. Meanwhile, strengthening HCPs' awareness of CLD and their capacity to differentiate between common lung diseases is essential in Kyrgyzstan to improve early diagnosis. Educational programs for HCPs therefore should be tailored to their needs and the local healthcare context. For example, in settings with adequate digital infrastructure, remote or e-learning approaches can be used, covering topics such as the identification of CLD using spirometry [8], especially for primary care HCPs who are usually the first to recognize CLD symptoms, as well as settings with limited access to qualified HCPs. In addition, continuing education on CLD management and clinical guidelines should be promoted to ensure up-to-date, evidence-based practice [9] and strong adherence to guidelines. When remote learning is not feasible, organizational support, training, and resources should be provided to facilitate multisectoral coordination and promote

evidence-based management and treatment [9]. Such efforts can support early recognition, timely professional care, and the delivery of context-sensitive health education.

7.2.2 Behavioral challenges associated with CLD across contexts

This thesis identified several CLD-related behavioral challenges in different contexts that appeared linked to cultural, socioeconomic and policy-related factors. These include risk behaviors such as smoking and the use of biomass and fossil fuels (**Chapter 2**), as well as other health-related behaviors such as delayed help-seeking among CMs (**Chapter 2**), restricted and experience-based helping behaviors among HCPs in Kyrgyzstan (**Chapter 3**), and patients' medication non-adherence (**Chapter 6**) in the Netherlands. For example, the higher prevalence and greater tolerance of smoking among men reported by Kyrgyz CMs (**Chapter 2**), reflect a longstanding link to gender norms and identity across regions worldwide for decades, where smoking always serves as a signifier of masculinity or femininity [2, 10-12]. Similarly, the continued use of solid fuels is usually driven by affordability and availability, although participants are aware of the harmful effects of HAP (**Chapter 2**). This indicates that economic factors can override knowledge in shaping risk behaviors. Regarding help-seeking behaviors, delays appear to reflect CMs' perceived severity of symptoms, ethnic background, with people with Russian ethnicities tending to seek help earlier than those with Kyrgyz ethnicities, as well as barriers to access, and trust in health services (**Chapter 2**). This finding adds to the limited evidence on help-seeking behaviors for CLD in this context and clarifies the underlying drivers, including individual perceptual, sociocultural and systemic factors. At the provider level, HCPs' helping behaviors are limited by local resources in Kyrgyzstan (**Chapter 3**), pointing to systemic challenges that affect the quality of care. In the HIC setting, however, despite the medication non-adherence of asthma patients, improvements were noted by using an easy-to-use digital inhaler, supported by patients' generally high eHL levels (**Chapter 6**). Together, these findings indicate that CLD-related behaviors vary across contexts and are closely related to sociocultural norms, economic factors, and health system administrations. Understanding these interactions is essential for designing effective health education and intervention strategies across diverse settings.

To effectively address these behavioral challenges, context-specific and coordinated efforts are required. At the individual level, improving awareness of CLD, including understanding risk factors such as smoking and HAP, seeking timely professional care, and adhering to long-term treatment is particularly relevant in low-resource settings like Kyrgyzstan. In contrast, in higher-resource settings such as the Netherlands, where baseline knowledge and healthcare access are higher, interventions may benefit more from targeting individuals' digital skills and optimizing engagement with digital tools. At the community level, interventions can leverage peer influence and social norms in settings where behaviors are socially embedded. For example, in Kyrgyzstan, involving

community leaders, teachers, group-based cessation activities, or local health education campaigns (**Chapter 2**, **Chapter 3**) may reframe smoking and HAP as shared community concerns rather than individual practices. In more digitally connected contexts, community influence may operate through online platforms such as social media. Given that few studies reported intervention mechanisms or theories in digital health education for CLD (**Chapter 5**), future interventions are recommended to incorporate and report established behavioral change techniques (BCTs) for sustained behavior change such as social support and goal setting [13]. At the health system and policy level, priorities also vary across contexts. In low-resource settings, strengthening healthcare infrastructure is essential to enable effective and sustained behavior changes. This includes improving healthcare access for CLD care, such as affordable and convenient health services, and investing in formal training for HCPs to enhance their capacity and competence in delivering evidence-based care (**Chapter 3**, **Chapter 6**). In HICs, the focus may shift toward optimizing the integration of digital health into routine care and addressing disparities in eHL. Overall, only when specific behavioral patterns, sociocultural contexts and health system capacities are considered together, can conditions be created to realistically support long-term behavioral change across diverse settings.

7.2.3 eHL, digital divide and the potential for eHealth in supporting CLD health education and behavior change

This thesis found a limited degree of eHL in the Chinese general population, highlighting the global issue of the digital divide (**Chapter 4**). The digital divide is characterized by unequal access to digital technologies, which may further widen existing health disparities [14, 15]. While previous studies explored eHL across diverse populations [16-18], individuals with limited digital access and older adults remain underrepresented, who usually have lower digital skills [19], face greater health inequities and poorer health outcomes [20]. To address the gap, **Chapter 4** intentionally included these populations by combining online and offline recruitment strategies. This approach improved sample representativeness and supported more inclusive research, enabling a better understanding of potential disparities and ensuring that findings are relevant to populations at risk of being excluded from eHealth. Notably, digital access was lower in the elderly and individuals with low socioeconomic position in China. This indicates that these groups might be left behind in the digital age and may not fully benefit from the potential effectiveness of eHealth, which widens disparities. Beyond sociodemographic factors such as age, educational and income level, this chapter identified additional factors related to eHL such as digital access, eHealth use and attitudes towards eHealth, with higher eHL observed among younger, more educated individuals, and those with greater access, more frequent eHealth use, and positive attitudes. This suggests that eHL is not merely an individual skill, but is shaped by or reflects broader structural conditions such as digital coverage, engagement and trust in eHealth. Therefore, improving eHL requires not only individual-level education but also addressing structural barriers such as unequal digital access and engagement to ensure equitable and inclusive benefits of eHealth.

While eHealth has demonstrated potential to improve awareness, health and behavioral outcomes for CLD (**Chapter 5, Chapter 6**), this thesis further clarified that such potential may not be fully realized in LMICs and that the effectiveness might vary across contexts. In **Chapter 5**, most digital health education programs were conducted in HICs, whereas some LMICs relied on traditional health education approaches like posters, brochures and face-to-face lectures (**Chapter 2, Chapter 3**). This aligns with the global disparity in digital access, as nearly 3 billion people worldwide were unconnected to the internet in 2023 [21] and could not benefit from eHealth. Moreover, lack of electricity and digital necessities such as data centers and dependable software platforms, limits the potential impact of eHealth in some LMICs [22]. This reflects the disparity in digital infrastructure between LMICs and HICs, which might further constrain the potential of eHealth. In **Chapter 6**, the digital inhaler program improved medication adherence for asthma, and its effectiveness was not moderated by participants' eHL or illness perceptions. The most plausible explanation is the user-friendly design of the program that functions passively and requires minimal digital skills. This implies that the potential of eHealth can be more equitably realized if the design carefully accounts for varying levels of complexity and user demands. Other eHealth interventions such as electronic health records and remote monitoring [23], requiring higher eHL to navigate, may therefore show different effectiveness among individuals. It may also reflect selection bias, as the sample included patients with sub optimally controlled asthma and generally had high eHL. Taken together, these findings highlight that the effectiveness of eHealth depends not only on their availability but also on how they are designed and implemented within specific contexts without reinforcing existing health inequalities. This is particularly relevant for populations with limited digital access and eHL, such as the elderly and individuals with low socioeconomic position (**Chapter 4**), for whom the benefits of eHealth warrant further investigation.

To address the digital divide and maximize the potential of eHealth, eHealth research should address systemic, intervention and user-related factors across multiple levels. The key factors underlying the digital divide range from 1) systemic factors, such as sociocultural norms and availability of support for using eHealth, 2) intervention-related factors such as usability and affordability, to 3) individual factors such as eHL levels and attitudes towards eHealth [24]. Previous eHealth research tended to examine individual-level barriers to eHealth uptake more extensively than systemic factors, which overlooked the systemic conditions that could exacerbate the digital divide among digitally marginalized populations [25]. Adopting a system-thinking perspective should therefore be prioritized in promoting eHealth. At the system level, actions are

critical to invest in digital infrastructure to ensure equitable access to eHealth, integrate eHL training into healthcare services, and strengthen capacity building for HCPs. At the intervention level, eHealth developers should identify individuals needing additional support, such as older adults and people with limited eHL, and actively engage diverse populations in the development and evaluation of eHealth solutions [24, 26] to enhance usability, comprehension, and adoption. This may include end users in content and interface design to ensure that eHealth is accessible, usable, and culturally appropriate, and in usability testing. At the user level, providing digital skills training and accessible support services, such as helpdesks, can help disadvantaged populations engage with and navigate eHealth effectively.

7.2.4 Methodological considerations

In **Chapter 2, Chapter 3 and Chapter 4**, a vignette describing a typical CLD case was introduced prior to data collection, without explicitly using the terms CLD, COPD, or asthma. Participants were then asked to describe their experiences, perceptions, and responses based on the vignette. The use of vignette-based methods provides a good example to explore participants' beliefs, perceptions and behaviors in response to standardized scenarios. Vignette methods are widely used in the social sciences to examine decision-making and behaviors in hypothetical real-life situations [27] but remain underused in healthcare research [28]. Compared with directly self-rating their knowledge, the use of vignettes can reduce social desirability bias [29], as participants are less likely to respond in ways that align with perceived norms or present themselves favorably, thereby allowing a more accurate assessment of their knowledge. By presenting a hypothetical but realistic CLD scenario, the vignette also allows for the examination of intended help-seeking behaviors among CMs and helping behaviors among HCPs in Kyrgyzstan. This is particularly valuable in other low-resource settings where CLD is prevalent, but awareness of CLD may be limited, and where direct observation of real-time behaviors is challenging. In addition, the same vignettes enable systematic comparison of how they interpreted CLD prevalence, severity, causes, as well as how they responded to the presented symptoms, allowing key behavioral patterns to be identified and summarized. However, vignette responses may not fully reflect actual behaviors in real-world settings but should rather be considered as strong predictors or proxies for such behavior [30]. In this thesis, vignettes were used across both survey and interview components, allowing data triangulation through different methods and thereby enhancing the validity of the findings.

By triangulating both qualitative and quantitative data, this thesis applied a mixed-methods approach. Qualitative methods should be viewed as complementary, rather

than competing approaches with quantitative methods. For example, questionnaires were used to investigate eHL, frequency of eHealth use (**Chapter 4**), as well as acceptability and usability (**Chapter 5**, **Chapter 6**). In addition, latent class analyses (**Chapter 1, Chapter 2**), and regression analyses (**Chapter 1-3, Chapter 5**) were applied to examine predictors and identify potential subgroups. These illustrate the value of quantitative methods (e.g., surveys, trials), which use numerical data to identify statistical trends or patterns, and analyze associations [31]. Unlike the quantitative methods, qualitative methods (e.g., interviews and focus groups) provide rich and detailed information about local people's experiences and perspectives, and reveal underlying reasons. For example, interviews and focus groups were used for exploring individuals' beliefs and perceptions (**Chapter 2**, **Chapter 3**), and helped explain why they perceived or behaved in certain ways. This suggests the values of qualitative methods in exploring the "how" and "what" questions that cannot be fully addressed through quantitative methods alone [32]. However, qualitative research is sometimes underestimated and misperceived as "too subjective", "samples are not representative", and of "low generalizability" [33], reflecting evaluation standards for quantitative research. In fact, qualitative research emphasizes empathy and reflexivity, requiring researchers to remain open-minded and sensitive to participants' verbal and non-verbal cues and emotions [34]. Therefore, qualitative and quantitative methods address different research questions, provide distinct perspectives and are evaluated using different standards. Future research should consider whether a single qualitative or quantitative method is sufficient and appropriate given the study aims and research questions, and make greater use of mixed methods to better capture contextual factors influencing health behaviors and to support effective eHealth interventions.

7.3 Strengths and limitations

Several strengths of this thesis are worth mentioning. First, involving diverse populations in both LMICs and HICs, including CMs, patients and HCPs, this thesis captures perspectives from varied sociocultural and health system settings. This enhances the relevance of the findings beyond a single context, highlights the importance of contextual factors, and aligns with practice recommendations for eHealth interventions that emphasize end-user involvement [26]. Second, the use of multiple study designs by integrating qualitative and quantitative evidence allows for a deeper and more nuanced understanding of health education needs and behavioral challenges regarding CLD. To enhance the rigor of the thesis, validated instruments and standardized data collection procedures were used where available, and qualitative

analyses were conducted in accordance with the Framework Method. Moreover, the mixed-methods design in **Chapters 2 and 3** enabled data triangulation, thereby strengthening the credibility and trustworthiness of the findings. Third, the findings of the thesis highlight the importance of equity in access to healthcare service and eHealth, reflecting the World Health Organization's initiatives on improving health equity [35] and promoting equitable, affordable and universal access to eHealth [36].

Meanwhile, several limitations should be acknowledged. First, the involvement of three countries as case studies limits the extent to which the findings can be interpreted as fully representative of a global perspective. However, they provided insights into observed beliefs, perceptions and behavioral patterns within each setting and how these patterns vary across contexts, thereby contributing to a broader understanding from a global perspective. Second, as some analyses in this thesis were based on secondary data, the findings may have limited the extrapolation to the current infrastructure and systemic context. However, given the relative stability of perceptual and behavioral patterns over time, these findings remain relevant to the local context and may be transferable to similar settings. Third, the predominantly observational and cross-sectional designs restrict causal inference regarding the relationships between illness perceptions, eHL, behavioral outcomes and sociodemographic characteristics. Nevertheless, these designs are appropriate for identifying key associations and informing the development of future health education strategies and behavior interventions. Finally, the sampling strategies and the use of questionnaires and qualitative methods may have introduced selection and reporting bias, potentially affecting the rigor of results. However, these methods were well suited to capturing individuals' beliefs, perceptions and behavioral patterns, which were not easily observed by objective measures alone.

7.4 Conclusions

Using case studies from Kyrgyzstan, China and the Netherlands, this thesis identified misbeliefs, misperceptions and several behavioral challenges about CLD across contexts. Results have important implications. Health education should be tailored to local needs and contexts, along with coordinated efforts at the individual, community and system levels to promote effective and sustained behavior change. Although eHealth has the potential to facilitate health education and behavior change, effectiveness may vary among individuals, especially those with limited digital access, low eHL and lower socioeconomic position. To address the digital divide and maximize the potential of eHealth, several strategies are recommended, including investing in digital infrastructure, engaging end users in the development and evaluation of eHealth, incorporating established BCTs, and supporting populations with lower digital skills.

Future research could consider vignette methods in low-resource settings to explore beliefs, perceptions and intended behaviors, and apply mixed qualitative and quantitative methods to gain a comprehensive perspective about users' needs, challenges and effectiveness of eHealth.

Abbreviations

BCT: behavioral change technique.
CLD: chronic lung disease.
CM: community member.
eHL: eHealth literacy.
HAP: household air pollution.
HCP: healthcare professional.
HIC: high-income country.
LMIC: low- and middle-income country.

References

1. Anastasaki M, van Bree EM, Brakema EA, Tsiligianni I, Sifaki-Pistolla D, Chatzea VE, et al. Beliefs, Perceptions, and Behaviors Regarding Chronic Respiratory Diseases of Roma in Crete, Greece: A Qualitative FRESH AIR Study. Frontiers in public health. 2022;10:812700.
2. Brakema EA, van der Kleij R, Poot CC, An PL, Anastasaki M, Crone MR, et al. Mapping low-resource contexts to prepare for lung health interventions in four countries (FRESH AIR): a mixed-method study. Lancet Glob Health. 2022;10(1):e63-e76.
3. Huang LM, Tan CY, Chen X, Jiang YJ, Zhou YR, Zhao H. A Qualitative Study on Illness Perception and Coping Behaviors Among Patients with Chronic Obstructive Pulmonary Disease: Implications for Intervention. Int J Chron Obstruct Pulmon Dis. 2024;19:2467-79.
4. Song X, Hallensleben C, Li B, Zhang W, Jiang Z, Shen H, et al. Illness Perceptions and Self-Management among People with Chronic Lung Disease and Healthcare Professionals: A Mixed-Method Study Identifying the Local Context. Healthcare (Basel, Switzerland). 2022;10(9).
5. Sun C, Kasteleyn MJ, Brakema EA, Poot CC, van der Kleij RM, Chavannes NH, et al. Beliefs, Perceptions, and Behaviors Regarding Chronic Lung Disease in Kyrgyzstan: A Mixed-method FRESHAIR Study. 2025:2025.11. 19.25338955.
6. Chronic respiratory diseases. https://www.who.int/health-topics/chronic-respiratory-diseases. Accessed 06 May 2023.
7. Brakema EA, van Gemert FA, Williams S, Sooronbaev T, Emilov B, Mademilov M, et al. Implementing a context-driven awareness programme addressing household air pollution and tobacco: a FRESH AIR study. NPJ primary care respiratory medicine. 2020;30(1):42.
8. Santoni A, Wait S, van Boven JFM, Desson Z, Jenkins C, Khoo EM, et al. Improving Care for People with Chronic Respiratory Diseases: Taking a Policy Lens. Advances in therapy. 2025;42(6):2569-86.
9. Brooks KY, Levy-Milne R. Educating frontline health workers to support evidence-based management and treatment for chronic obstructive pulmonary disease patients: A literature review. Can J Respir Ther. 2022;58:127-35.
10. Hadisuyatmana S, Prayudha A, Indarwati R, Efendi FJJoGPT. The Correlation between masculinity and smoking behavior among adolescent in Surabaya. 2020;12(2):795-804.
11. Davey G, Zhao X. 'A real man smells of tobacco smoke'--Chinese youth's interpretation of smoking imagery in film. Soc Sci Med. 2012;74(10):1552-9.
12. Hunt K, Hannah MK, West P. Contextualizing smoking: masculinity, femininity and class differences in smoking in men and women from three generations in the west of Scotland. Health Educ Res. 2004;19(3):239-49.
13. Fujii M, Nakano J, Tanaka Y, Tonosaki A. Effects of self-management interventions with behavior-change support on long-term adherence in patients with chronic respiratory diseases: A systematic review. GHM Open. 2022;2(1):12-24.
14. Lythreatis S, Singh SK, El-Kassar A-N. The digital divide: A review and future research agenda. Technological Forecasting and Social Change. 2022;175.
15. The Lancet Healthy L. Tackling the Digital Divide. Lancet Healthy Longev. 2021;2(10):e601.
16. Huang CL, Chiang CH, Yang SC. eHealth Literacy and Beliefs About Medicines Among Taiwanese College Students: Cross-sectional Study. JMIR medical informatics.

2021;9(11):e24144.
17. Park SY, Chung S. E-health literacy and associated factors among Korean adults during the COVID-19 pandemic: age-group differences. Health Promot Int. 2023;38(5).
18. Tesfa GA, Yehualashet DE, Ewune HA, Zemeskel AG, Kalayou MH, Seboka BT. eHealth Literacy and its Associated Factors Among Health Professionals During the COVID-19 Pandemic in Resource-Limited Settings: Cross-sectional Study. JMIR formative research. 2022;6(7):e36206.
19. Zonneveld MB, Pol MC, Kasteleyn MJ, Achterberg WP, van Dam van Isselt EF. Screening the Digital Skills of Patients in Geriatric Rehabilitation: Multicenter Cross-Sectional Study. JMIR formative research. 2026;10:e84425.
20. Hua Z, Yuqing S, Qianwen L, Hong C. Factors Influencing eHealth Literacy Worldwide: Systematic Review and Meta-Analysis. J Med Internet Res. 2025;27:e50313.
21. Broadband Infrastructure, Access and Use. https://www.worldbank.org/en/topic/digital/brief/digital-infrastructure. Accessed 18 January 2026.
22. Al Meslamani AZ. Barriers to digital endpoints in data collection in low and middle-income countries. Expert Rev Pharmacoecon Outcomes Res. 2024;24(6):701-3.
23. Verweel L, Newman A, Michaelchuk W, Packham T, Goldstein R, Brooks D. The effect of digital interventions on related health literacy and skills for individuals living with chronic diseases: A systematic review and meta-analysis. Int J Med Inform. 2023;177:105114.
24. Western MJ, Smit ES, Gultzow T, Neter E, Sniehotta FF, Malkowski OS, et al. Bridging the digital health divide: a narrative review of the causes, implications, and solutions for digital health inequalities. Health Psychol Behav Med. 2025;13(1):2493139.
25. Coetzer JA, Loukili I, Goedhart NS, Ket JCF, Schuitmaker-Warnaar TJ, Zuiderent-Jerak T, et al. The potential and paradoxes of eHealth research for digitally marginalised groups: A qualitative meta-review. Soc Sci Med. 2024;350:116895.
26. van Vliet MHM, van Eersel RA, Poot CC, Faber JS, Aardoom JJ, Meijer E, et al. A practical step-by-step approach for patient and public involvement in eHealth intervention research: Lessons learned from three case projects. Internet Interventions. 2025:100896.
27. Renold EJBRC. Using vignettes in qualitative research. 2002;3(3-5).
28. Sheringham J, Kuhn I, Burt J. The use of experimental vignette studies to identify drivers of variations in the delivery of health care: a scoping review. BMC Med Res Methodol. 2021;21(1):81.
29. Bispo Junior JP. Social desirability bias in qualitative health research. Rev Saude Publica. 2022;56:101.
30. Evans SC, Roberts MC, Keeley JW, Blossom JB, Amaro CM, Garcia AM, et al. Vignette methodologies for studying clinicians' decision-making: Validity, utility, and application in ICD-11 field studies. Int J Clin Health Psychol. 2015;15(2):160-70.
31. What Is Qualitative vs. Quantitative Study? https://www.nu.edu/blog/qualitative-vs-quantitative-study/. Accessed 25 February 2026.
32. Pyo J, Lee W, Choi EY, Jang SG, Ock M. Qualitative Research in Healthcare: Necessity and Characteristics. J Prev Med Public Health. 2023;56(1):12-20.
33. Nevedal AL, Kowalski CP, Finley EP, Fix GM, Hamilton AB, Koenig CJ. Optimizing

qualitative methods in implementation research: a resource for editors, reviewers, authors, and researchers to dispel ten common misperceptions about qualitative research methods. Implement Sci. 2025;21(1):4.
34. The Ultimate Guide to Qualitative Research - Part 1: The Basics. https://atlasti.com/guides/qualitative-research-guide-part-1/qualitative-research. Accessed 15 March 2026.
35. Health equity. https://www.who.int/health-topics/health-equity#tab=tab_3. Accessed 05 February 2026.
36. Global strategy on digital health 2020-2027: World Health Organization; 2025.

PhD Portfolio

The PhD trajectory – an overview

CRediT statement

Bibliography

Academic training and activities

PhD Trajectory – an overview

During **the first year** of my PhD, my work mainly focused on a scoping review about digital health education for chronic lung disease (CLD) (Chapter 5), while completing all mandatory courses, such as Basic Biostatistics, Responsible Research and Scientific Conduct for PhDs. After settling in the Netherlands, I developed the review protocol, formulated research questions, and read extensive similar literature reviews to familiarize myself with digital health and learned from existing literature. I also established collaborations with peer researchers who contributed to the literature screening process.

Throughout this period, I acquired substantial knowledge of digital health in CLD and gained valuable experience in conducting review studies. This included understanding the differences between scoping reviews and systematic reviews, formulating specific and feasible research questions, evaluating studies with different designs using standardized appraisal tools and reporting checklists, applying the AI-based software ASReview for literature screening, and identifying relevant outcomes for implementing and evaluating eHealth interventions. Overall, this year marked the beginning of a new chapter in my academic career as a PhD candidate. In addition, I adapted to a new living and working environment within a different cultural and linguistic context, which contributed significantly to both my professional and personal growth.

During **the second year**, I focused on a survey study examining eHealth literacy (eHL) in China (Chapter 4). Through reviewing the literature, I found that eHL remained a relatively new concept in the Chinese context and that most existing studies relied solely on online surveys. As a result, certain population groups, such as individuals without digital access and those with lower socioeconomic positions, may have been underrepresented. To address this gap, I took the lead in developing a survey protocol that incorporated both online and offline data collection methods and preparing documents for ethical approval. I also developed bilingual (English and Chinese) questionnaires and established a collaboration with researchers from the School of Nursing at Wuhan University.

Following questionnaire development, I conducted a small-scale pilot test to assess the quality, clarity, and readability of the survey instruments. After finalizing the study materials, the necessary documents were prepared and submitted for ethical approval. Meanwhile, I organized an online training session for the investigators, covering the study objectives, questionnaire introductions, and guidance on assisting participants completing the survey in person. After data collection was completed, I began the

processes of data cleaning and statistical analysis. During this stage, I further developed my quantitative research skills by learning and applying statistical techniques in SPSS. This project provided me with hands-on experience in survey design, cross-cultural questionnaire development, fieldwork coordination, ethical procedures, and quantitative data analysis.

During **the third year**, I worked with a cross-cultural dataset collected in Kyrgyzstan in 2016 as part of the FRESH AIR project, which explored local beliefs, perceptions, and behaviors related to CLD (Chapter 2 and 3). Although the study protocol and primary findings had already been published, I took the lead in developing new research questions, applying additional statistical approaches and conducting data analyses. Before data analysis, I completed the course on qualitative methods and learned how to conduct latent class analysis in R. Throughout the project, I consulted with researchers who had previously been involved in the study to ensure a clear understanding of the procedures and appropriate interpretation of the findings. This project took more time due to the complexity of working with qualitative and quantitative data, involving both community members and healthcare professionals. Therefore, I formulated and forwarded my idea to split all data across two papers while keeping the mixed-method study design. Working with interviews and focus groups offered a deeper understanding of participants' illness perceptions and health-related behaviors, complementing the patterns observed in quantitative data. This experience fostered a stronger connection to the lived experiences and struggles of the study participants, and reminded me of people and communities in my hometown, further strengthening my interest in medical anthropology and academia.

During this year, I also began presenting my research at international conferences, which allowed me to share my work with a broader audience and engage with researchers from different disciplines and backgrounds. As I aimed to complete my PhD within the duration of my contract, I increasingly worked on projects in parallel. For example, while finalizing analyses for the FRESHAIR project, I applied for access to another dataset and completed a statistical course Mediation and Moderation Analyses to prepare for the next project. This period marked a transition toward greater independence in managing research activities, collaborating with multidisciplinary researchers and planning subsequent studies, while also helping me develop a clearer sense of my research interests and future academic direction.

During the **final year**, my work primarily focused on completing ongoing projects and writing my thesis. Given my interest in interventional eHealth research, I conducted a post-hoc analysis based on a cluster randomized controlled trial in Dutch primary care to investigate whether illness perceptions and eHL moderated the effectiveness of a

digital inhaler program for asthma patients (Chapter 6). Compared with my earlier projects, this study progressed more efficiently due to its quantitative nature and the research experience I had accumulated throughout my PhD. Although a minor adjustment to the data analysis was made in the late phase, the study helped develop my skills in longitudinal data analysis, repeated measures, and the design and evaluation of intervention studies. During the thesis writing phase, I integrated all my research projects, ensuring a clear flow and coherence across chapters, and highlighting the novelty of my research and its practical relevance for global and digital health (Chapter 1 and 7). After completing my thesis, I had the opportunity to attend a masterclass on co-design, health literacy, and equity for systems and service improvement, as well as a summer school on One Health. These experiences further enhanced my knowledge of health literacy interventions and strengthened my system-thinking perspective on tackling complex health challenges.

Throughout my PhD trajectory, I deepened my understanding of CLD, digital health, and healthcare challenges in different settings from a global perspective. Meanwhile, I took the lead in data analyses, manuscript preparation, writing, and submission, while maintaining proactive and well-coordinated collaboration with supervisors, co-authors, and external collaborators. Beyond my thesis work, I delivered lectures on digital health education and data analyses in healthcare to Chinese students and Kyrgyz researchers. I also disseminated my research findings at conferences, receiving a Best Oral Presentation Award in recognition of one of my presentations. I successfully secured internal and external funding (e.g., Erasmus+ funding, Leiden University Fund) to support my academic training and conference participation. With some remaining time within my PhD period, I am currently exploring new research ideas and actively seeking potential postdoctoral opportunities and grant applications for the next career step.

CRediT statement for the thesis

Chapter	Type	Short title	Conceptualization	Data curation	Formal analysis	Funding acquisition	investigation	methodology	Project administration	resources	Software	Supervision	Validation	Visualization	Writing-original draft	Writing-review &editing	Preregistered	Preprinted	Published
1	Introduction	General introduction	■												■	■			
2	PhD project chapter	Beliefs, perceptions and behaviors in CMs	■		■		■	■						■	■	■	✓	✓	
3	PhD project chapter	Beliefs, perceptions and behaviors in HCPs	■	■	■		■	■			■			■	■	■	✓	✓	
4	PhD project chapter	eHealth literacy survey in China	■	■					■	■		■			■	■			✓
5	PhD project chapter	Digital Health Education	■	■	■		■	■	■		■		■	■	■	■		✓	✓
6	PhD project chapter	Moderation analyses	■	■	■		■	■	■		■		■	■	■	■	✓		
7	Discussion	General discussion	■												■	■			

CM: community member.
HCP: healthcare professional.

Bibliography

Publications and submitted manuscripts in this thesis

(1) **Sun C,** Kasteleyn MJ, Brakema EA, Poot CC, van der Kleij RM, Chavannes NH, Mademilov M, Sooronbaev T, Meijer E. Beliefs, Perceptions, and Behaviors Regarding Chronic Lung Disease in Kyrgyzstan: A Mixed-method FRESHAIR Study. doi: https://doi.org/10.1101/2025.11.19.25338955. (preprinted and under review; npj Primary Care Respiratory Medicine)

(2) **Sun C**, Meijer E, Brakema EA, Mademilov M, Poot CC, Sooronbaev T, Chavannes NH, van der Kleij RM, Kasteleyn MJ. Beliefs, Perceptions, and Helping Behaviors Regarding Chronic Lung Disease among Healthcare Professionals in Kyrgyzstan: A Mixed-method FRESHAIR Study. doi: https://doi.org/10.21203/rs.3.rs-9140844/v1. (preprinted and under review; BMC Health Services Research)

(3) **Sun C,** Kasteleyn M.J, van Boven FMJ, Gerritsma YH, Kocks JWH, Poot CC, van de Hei S, van den Berg L, Chavannes NH, Meijer E. Illness perceptions and eHealth literacy on effectiveness of a digital inhaler program for asthma in the Netherlands: post-hoc moderation analyses of a cluster randomized controlled trial. (under revision; JMIR mHealth and uHealth)

(4) **Sun C**, Meijer E, Chavannes NH, Dai H, Li X, Wang Y, Wu L, Zhang Q, Kasteleyn MJ. eHealth literacy in the general population: a cross-sectional study in China. BMC Public Health 25, 211 (2025). https://doi.org/10.1186/s12889-025- 21389-0.

(5) **Sun C**, Dai H, M.J.J. van der Kleij RM, Li R, Wu H, Hallensleben C, Willems SH, Chavannes NH. Digital Health Education for Chronic Lung Disease: Scoping Review. Journal of Medical Internet Research 2025. https://doi.org/10.2196/53142.

Other publications

(1) **Sun C***, Zhu B*, Zhu S, Zhang L, Du X, Tan X. Risk Factors Analysis of Bone Mineral Density Based on Lasso and Quantile Regression in America during 2015–2018. International Journal of Environmental Research and Public Health. 2022; 19(1):355. https://doi.org/10.3390/ijerph19010355.

(2) **Sun C***, Liu Y*, Huang Y, Li B, Rang W. Colorectal Cancer Incidence and Mortality Trends and Analysis of Risk Factors in China from 2005 to 2015. International Journal of General Medicine. 2021;14:9965-9976. https://doi.org/10.2147/IJGM.S344448.

(3) Zhu S*, **Sun C***, Zhang L, Du X, Tan X, Peng S. Incidence Trends and Survival Prediction of Malignant Skin Cancer: A SEER-Based Study. International Journal of General Medicine. 2022;15, 2945–2956. https://doi.org/10.2147/IJGM.S340620.

(4) Dai H, **Sun C**, Chen J, Zhou X, Li H, Martin P, Zhang Q. The mediating effect of eHealth literacy on the relationship between health personality and quality of life in community-dwelling older adults. Geriatric Nursing, 56, 237-243. https://doi.org/10.1016/j.gerinurse.2024.02.002.

(5) Dai H, **Sun C**, Xu S, Farina, Huang X, Wang Y, Zhang Q, Shen H. Cultural adaptation and psychometric evaluation of the fear and avoidance of memory loss scale in a Chinese

context. Aging & Mental Health, 29(6), 1144–1151. https://doi.org/10.1080/13607863.2025.2452931.

(6) Dai H, Shen H, Versluis A, **Sun C**, Dubbeldeman EM, Chavannes NH, Aardoom JJ. Interventions on fear of dementia among middle-aged and older adults: A scoping review. Alzheimer's & Dementia: Behavior & Socioeconomics of Aging. 2025; e70020. https://doi.org/10.1002/bsa3.70020.

(7) Li B*, Liu Y*, Peng J, **Sun C**, Rang W. Trends of Esophageal Cancer Incidence and Mortality and Its Influencing Factors in China. Risk Management and Healthcare Policy, 14, 4809–4821. https://doi.org/10.2147/RMHP.S312790.

(8) Li G, Xu D, Hu F, Xu M, Zhang L, Du X, Zhang L, **Sun C**, Xie Y, Tan X. Impact of the coronavirus disease 2019 lockdown on Schistosoma host Oncomelania hupensis density in Wuhan. Acta Tropica 2022, 226:106224. https://doi.org/10.1016/j.actatropica.2021.106224.

Overview of academic training and activities

Completed courses and other training

Mandatory courses

- 2023 Basic Methods and Reasoning in Biostatistics - Exemption granted, Leiden University
- 2023 Leiden University Onboarding Program Inform & Connect (2 activities)
- 2023 Responsible Research (2 activities), Leiden University
- 2022 Workshop Scientific Conduct for PhDs, Leiden University

Other courses and training

- 2026 "One Health" Una Europa Summer School, University College Dublin

  Funded by *Erasmus+ grant for staff mobility training*
- 2026 Masterclass on Co-design, Health literacy, and Equity for Systems and Service Improvement, University of Oslo
- 2025 Healthcare in Shape Symposium, Technology University of Delft
- 2025 Mediation and Moderation Analysis, Leiden University
- 2025 Career Planning for PhDs and Postdocs, Leiden University
- 2024 Qualitative Research in Health, Leiden University
- 2023 Qualitative Interview, Leiden University
- 2023 Advanced Project Management for PhD candidates, Leiden University
- 2023 Online Presenting Skills for PhDs, Leiden University
- 2023 Academic Writing for PhDs, Leiden University
- 2023 Effective Communication, Leiden University

Presentations

Conferences

- 2026 11th International Digital Public Health Conference (Barcelona, Spain, funded by *Leiden University Fund*)

  Oral presentation: *Moderation analyses of illness perceptions and eHealth literacy on effectiveness of a digital inhaler program in asthma patients: a post-hoc analysis of the ACCEPTANCE trial*
- 2025 Asian Conference on Implementation Science (Guangzhou, China)

  Best Oral Presentation Award: *Beliefs, Perceptions, and Behaviors Regarding Chronic Lung Disease in Kyrgyzstan: A Mixed-method FRESHAIR Study*

- 2025 10th International Digital Public Health Conference (Madeira, Portugal) Oral and poster presentation: *Digital Health Education for Chronic Lung Disease: Scoping Review*

Lectures

- 2025 Introduction to Digital Health Education (online, Guangzhou Medical University)
- 2024 How to formulate a good research question, aims and objectives (online, Kyrgyz Medical Faculty)
- 2024 Data Analyses in Healthcare Research (online, Kyrgyz Medical Faculty)

Appendixes

Summary

Nederlandse samenvatting

总结

Dankwoord

Curriculum vitae

Appendixes

Summary

Chronic lung disease (CLD) poses a large health and economic burden worldwide and is unevenly distributed across regions and populations. Moreover, research funding is disproportionately concentrated in high- income countries (HICs). Given the burden of CLD, promoting health education and behavior change is essential to increase individuals' understanding of CLD and support them in adopting healthy behaviors, such as seeking timely healthcare and adhering to prescribed medications. Across diverse global contexts, challenges such as limited awareness of CLD, prevalent and difficult-to-change risk behaviors and inappropriate CLD-related behaviors among individuals and healthcare professionals (HCPs), remain in translating health education into effective and sustained behavior change. With the increasing integration of information and communication technology in healthcare, eHealth seems to demonstrate potential in promoting health education and behavior change by increasing the accessibility and efficiency of healthcare delivery without time or geographical barriers. However, the effectiveness of eHealth might vary between contexts and individuals due to differences in healthcare systems, digital coverage, and individual characteristics such as eHealth literacy (eHL) level, which refers to individuals' abilities to access, understand, appraise and apply online health information. Drawing on three countries with distinct socioeconomic, geographic and healthcare contexts, this thesis aimed to provide a global perspective on health education needs and behavioral challenges related to CLD, and to examine the potential of eHealth for supporting CLD health education and behavior change. Specifically, this thesis had the following three aims:

1) to explore beliefs, perceptions and behaviors related to CLD;

2) to assess eHL and its associated factors;

3) to evaluate the potential of eHealth for CLD health education and behavior change.

Chapter 1 provided a general introduction about the global burden of CLD, importance and challenges of health education and behavior change for CLD, the potential of eHealth regarding CLD, and the three settings in which empirical studies were performed.

Chapter 2 and **Chapter 3** explored CLD-related beliefs, perceptions and behaviors among community members (CMs) and HCPs in Kyrgyzstan. Using a brief textual scene describing a typical CLD-like condition, and integrating data from questionnaires, interviews and focus groups, these two chapters provided context-specific insights into how local people perceived CLD and its causes, as well as how they responded to CLD-

like conditions. Findings showed that CMs usually perceived CLD symptoms as acute, infectious conditions, and attributed them to cold and smoking. Despite awareness of the health risks, smoking remained prevalent among CMs, along with the widespread use of solid fuels for cooking and heating with limited ventilation due to resource constraints. A delayed help-seeking pattern was observed, such as the preference for traditional medicine, and self-medication before seeking formal care. CMs with longer duration of education, being unemployed, and living in the lowlands tended to have more negative illness perception scores, which meant that they perceived CLD as more threatening and burdensome. Among HCPs, challenges were noticed in differentiating CLD from other respiratory diseases, and HCPs provided restricted and experience-based helping behaviors due to lack of resources. For example, HCPs referred patients to better-equipped places, prescribed antibiotics (which reflected uncertainty in recognizing CLD and might not be always appropriate for CLD treatment) and rarely used guidelines. Physicians appeared to provide more helping behaviors for CLD than nurses. These findings suggest that CLD-related beliefs, perceptions and behaviors might vary in contexts, shaped by socio-economic, cultural, policy-related and health system factors.

Chapter 4 investigated eHL and its associated factors in the Chinese general population. Online and offline surveys were used to improve inclusiveness and representativeness. The sample showed limited eHL and CLD knowledge on average, generally reported positive expectations to eHealth, perceiving it as easy to use and useful. While digital access was common overall, notable disparities were noticed between the elderly and those with a low socioeconomic position, and other groups. Younger age, higher education and income level, having digital access, more frequent eHealth use, and a more positive attitude towards eHealth were associated with higher eHL. This chapter highlights the need to improve eHL and CLD knowledge, as well as the digital access among the vulnerable population. The identified determinants of eHL provide a basis for designing tailored health education and eHealth interventions to meet the needs and preferences of different population groups.

Chapter 5 provided an overview of existing literature on digital health education (DHE) for CLD, and reported delivery mediums, educational content, intervention mechanisms, and outcomes of DHE. The findings indicate an increasing publication trend in this field, but mostly in HICs. Websites and mobile applications were the most widely used mediums, mainly focusing on teaching people how to manage their health by themselves, yet intervention mechanisms were rarely mentioned. Most studies found that DHE helped improve patients' understanding of CLD, health outcomes, lifestyle, mental and social well-being, while also being practical to use, well accepted by

participants, and highly rated in terms of satisfaction. Only two studies reported cost-effectiveness, but neither provided a clear comparison of costs before and after DHE. This demonstrates the potential of eHealth in supporting CLD health education, while also revealing important gaps in the literature. In particular, there is a need for greater attention to low- and middle-income countries, intervention mechanisms and cost-effectiveness outcomes.

Building on a cluster randomized trial in Dutch primary care, **Chapter 6** examined whether illness perceptions and eHL affected effectiveness of a digital inhaler program among asthma patients, as well as how illness perceptions and eHL were related to demographics. In this trial, the intervention group used a digital inhaler program with self-monitoring and medication adherence reminders, while the control group used a passively monitored inhaler without feedback. Previously, the program proved to be effective in improving asthma control and medication adherence. Our study showed that illness perceptions and eHL did not affect the effectiveness. This implies the user-friendly program may achieve equivalent effectiveness across patients with different illness perceptions and eHL. This result might also be partly because the sample had generally high eHL levels. In addition, we found that people with younger age were more likely to have better eHL. These findings provide guidance for evaluating other factors to identify subgroups that benefit from eHealth interventions most or require additional support to use them, and highlight the potential equitable effectiveness of eHealth interventions in different groups.

Chapter 7 presents the general discussion of this thesis. By integrating findings across diverse contexts and study designs, this thesis identified beliefs, perceptions and several behavioral challenges regarding CLD among CMs and HCPs, assessed eHL and its associated factors, and examined the potential for eHealth in supporting CLD health education and behavior change. Despite the demonstrated benefits of eHealth, those with limited digital access, low eHL and lower socioeconomic position might benefit less. These findings underscore the importance of tailoring health education to local needs and contexts, for example using existing resources and simple, locally easy-to-understand language, engaging key stakeholders such as community members, leaders, teachers, HCPs, policy-makers and designers, and applying behavior change techniques to promote effective and sustained behavior change. To address the digital divide and maximize the potential for eHealth, it is recommended to invest in digital infrastructure, engage end users in the development and evaluation of eHealth, incorporate established behavior change techniques, and provide technical support for populations with lower digital skills.

Samenvatting

Chronische longziekten zorgen wereldwijd voor een grote gezondheids- en economische last. De prevalentie van chronische longziekten is ongelijk verdeeld tussen regio's en bevolkingsgroepen. Het grootste deel van het onderzoeksgeld gaat echter naar hoge-inkomenslanden. Gezien de hoge ziektelast van chronische longziekten is het belangrijk om gezondheidsvoorlichting en ondersteuning bij gedragsverandering te verbeteren, zodat mensen chronische longziekten beter begrijpen en gezondere keuzes maken, zoals op tijd medische hulp zoeken en hun medicijnen goed gebruiken. In verschillende landen blijft het lastig om gezondheidsvoorlichting om te zetten in blijvend gezond gedrag. Dit komt bijvoorbeeld door weinig kennis over chronische longziekten, moeite om risicogedrag te veranderen, en niet-helpend gedrag rond chronische longziekten bij zowel patiënten als zorgverleners. Door de steeds grotere rol van informatie- en communicatietechnologie in de zorg lijkt eHealth veel mogelijkheden te bieden voor gezondheidsvoorlichting. Het kan de zorg toegankelijker en efficiënter maken, zonder beperkingen van tijd of afstand. Toch kan de effectiviteit van eHealth verschillen tussen landen en personen, door verschillen in zorgsystemen, digitale toegang en persoonlijke kenmerken zoals eHealth-geletterdheid. eHealth-geletterdheid is het vermogen om online gezondheidsinformatie te vinden, te begrijpen, te beoordelen en toe te passen.

Dit proefschrift had als doel om wereldwijd inzicht te geven in de behoefte aan gezondheidsvoorlichting en gedrag rond chronische longziekten, en het potentieel van eHealth voor gezondheidsvoorlichting en gedragsverandering te onderzoeken. Hiervoor werd onderzoek gedaan in drie landen met verschillende sociaaleconomische, geografische en zorgcontexten. De drie doelstellingen waren:

1. het verkennen van overtuigingen, percepties en gedrag rond chronische longziekten;

2. het meten van eHealth-geletterdheid en de factoren die daarmee samenhangen;

3. het beoordelen van het potentieel van eHealth voor gezondheidsvoorlichting en gedragsverandering bij chronische longziekten.

Hoofdstuk 1 introduceerde de wereldwijde ziektelast van chronische longziekten, het belang en de uitdagingen van gezondheidsvoorlichting en gedragsverandering, en het potentieel van eHealth.

Hoofdstuk 2 en **Hoofdstuk 3** onderzochten de overtuigingen, percepties en het gedrag rond chronische longziekten bij burgers en zorgverleners in Kirgizië. Met behulp van reacties op een korte beschrijving van een persoon met typische chronische

longklachten, aangevuld met data uit vragenlijsten, interviews en focusgroepen, brachten deze hoofdstukken in kaart hoe mensen chronische longziekten zien en erop reageren. Symptomen werden vaak gezien als tekenen van een acute of besmettelijke ziekte en toegeschreven aan kou en roken. Hoewel er voldoende kennis was over de risico's, bleven roken, het gebruik van vaste brandstoffen om te koken, en verwarmen met weinig ventilatie veel voorkomen door beperkte middelen. Ook werd vaak pas laat medische hulp gezocht, bijvoorbeeld nadat eerst traditionele geneeskunde of zelfmedicatie was geprobeerd. Mensen met meer opleiding, werklozen en mensen in laaglandgebieden hadden vaker negatievere ziektepercepties, wat betekent dat zij chronische longziekten als bedreigender en meer belastend ervoeren. . Zorgverleners hadden moeite om chronische longziekten te onderscheiden van andere longaandoeningen. Hun handelen was door gebrek aan middelen vaak beperkt en gebaseerd op ervaring. Dit ging bijvoorbeeld om doorverwijzen, antibiotica voorschrijven en beperkt gebruik van richtlijnen. Artsen leken meer hulp te bieden dan verpleegkundigen.

Hoofdstuk 4 onderzocht eHealth-geletterdheid en gerelateerde factoren in de Chinese bevolking. Zowel online als offline vragenlijsten werden gebruikt. Gemiddeld waren de eHealth-geletterdheid en kennis over chronische longziekten beperkt, maar er was wel een redelijk positieve houding tegenover eHealth. Hoewel digitale toegang over het algemeen goed was, waren er duidelijke verschillen tussen bevolkingsgroepen, waarbij ouderen en mensen met een lagere sociaaleconomische statuslager scoorden. Jongere leeftijd, hoger onderwijs, hoger inkomen, digitale toegang, vaker gebruik van eHealth en een positievere houding tegenover eHealth waren gerelateerd aan betere eHealth-geletterdheid.

Hoofdstuk 5 gaf een overzicht van bestaande literatuur over digitale gezondheidsvoorlichting bij chronische longziekten. Websites en mobiele apps werden het meest gebruikt, vooral gericht op zelfmanagement. Hoe deze interventies precies werken werd vaak niet goed uitgelegd. De meeste studies lieten positieve effecten zien op kennis, gezondheid, leefstijl en welbevinden, en deelnemers waren meestal tevreden. Slechts twee studies bekeken kosteneffectiviteit, maar die maakten geen duidelijke kostenvergelijking voor en na de interventie. Dit laat zien dat eHealth veel potentie heeft, maar dat er nog belangrijke kennishiaten zijn.

Hoofdstuk 6 onderzocht in een Nederlandse eerstelijnsstudie of ziektebeleving en eHealth-geletterdheid invloed hadden op de werking van een digitale inhalator-app bij astmapatiënten. De interventiegroep gebruikte een digitale inhalator met feedback en herinneringen, terwijl de controlegroep inhalator gebruikte die alleen monitorde maar

geen ondersteuning bood. Eerder bleek dat het programma astmacontrole en medicatiegebruik verbeterde. In deze studie bleek dat ziektepercepties en eHealth-geletterdheid geen invloed hadden op de effectiviteit van het programma. Wel bleek jongere leeftijd samen te hangen met een hogere eHealth-geletterdheid.

In **Hoofdstuk 7** werden de resultaten geïntegreerd en besproken. Dit proefschrift liet zien dat er duidelijke verschillen zijn in overtuigingen, percepties en gedrag rond chronische longziekten tussen groepen mensen en landen. eHealth heeft veel potentie, maar mensen met lage digitale vaardigheden, beperkte digitale toegang en een lagere sociaaleconomische status profiteren mogelijk minder. Daarom is het belangrijk om gezondheidsvoorlichting aan te passen aan lokale contexten en behoeftes, bijvoorbeeld door inzet van bestaande middelen, eenvoudige en begrijpelijke taal te gebruiken, en belangrijke belanghebbenden zoals leden van lokale gemeenschappen, leraren, zorgverleners en beleidsmakers, te betrekken. Ook is het belangrijk om te investeren in digitale infrastructuur, gebruikers te betrekken bij het ontwerpen van eHealth, gedragstechnieken toe te passen en extra ondersteuning te bieden aan mensen met lage digitale vaardigheden.

总结

慢性肺疾病（chronic lung disease, CLD）在全球范围内造成了严重的健康与经济负担，且在不同地区与人群之间分布不均衡。此外，相关研究资金主要集中于高收入国家。鉴于 CLD 的疾病负担，促进健康教育与行为改变至关重要，以帮助人们更好地理解 CLD，并养成健康行为，例如及时就医和遵医嘱用药。然而，在全球不同情境中，如何通过健康教育实现有效且可持续的行为改变，仍面临诸多挑战，如患者和医护人员（healthcare professionals, HCPs）CLD 认知不足，危险行为普遍且难以改变，还有其他不当行为。随着信息与通信技术在医疗卫生领域的不断融合，电子健康（eHealth）似乎在促进 CLD 健康教育和行为改变方面展现出潜力，能突破时间与地域限制，提高医疗服务的可及性与效率。然而，由于医疗体系、数字基础设施覆盖以及个体特征的差异，如电子健康素养（eHealth literacy, eHL）水平，即获取、理解、评估和运用在线健康信息的能力，eHealth 的效果可能因情境与个体而异。基于在社会经济、地理与医疗卫生方面存在显著差异的三个国家，本论文旨在从全球视角探讨 CLD 相关的健康教育需求与行为挑战，并评估 eHealth 在支持 CLD 健康教育与行为改变的潜力。具体而言，本论文包括以下三个研究目标：

1）探索与 CLD 相关的信念、意识与行为；

2）评估 eHL 及其相关因素；

3）评估 eHealth 在 CLD 健康教育与行为改变中的潜力。

第一章介绍了 CLD 的全球疾病负担、CLD 健康教育与行为改变的重要性及其挑战、eHealth 的潜力，以及本论文实证研究的三个场景。

第二章与**第三章**探讨了吉尔吉斯斯坦社区居民与医护人员 CLD 相关的信念、意识及行为。通过描述一个典型 CLD 症状的情景案例，并结合问卷、访谈与焦点小组数据，这两章深入探讨了当地居民对 CLD 及其病因的理解，以及他们面对类似 CLD 症状时的应对方式。研究结果显示，当地居民通常将 CLD 症状视为急性传染性疾病，并将其归因于感冒和吸烟。尽管居民意识到吸烟对健康的危害，但吸烟行为仍较为普遍。同时，由于资源受限，居民常用固体燃料进行烹饪和取暖，且通风有限。研究还观察到居民的延迟就医行为，例如在寻求正规医疗服务前，优先采用传统疗法或自行用药。受教育年限较长、失业以及住在低地地区的居民，其疾病意识评分更趋负面，即他们认为 CLD 给自己带来的威胁更大、负担更重。在医护人员中，存在将 CLD 与其他呼吸系统疾病区分困难的问题。由于资源不足，他们提供的帮助有限，更多地依赖经验，例如将患者转诊至设施更完善的医疗机构，开具抗生素（这反映了不能准确识别 CLD 的问题，且往往不是合理的治疗手段），且很少使用临床指南。与护士相比，医生似乎为 CLD 患者提供了更多的帮助。这些结果表明，CLD 相关的信念、意识与行为因环境而异，并受到社会经济、文化、政策及卫生体系等多重因素的影响。

第四章调查了中国普通人群的 eHL 水平及其相关因素。研究结合了线上与线下调查，以

提高样本的多样性与代表性。结果显示，研究对象整体 eHL 水平较低，CLD 知识储备有限，但整体上对 eHealth 持积极态度，认为其操作简单且实用。尽管总体上数字设备与网络接入较为普及，但老年人、低社会经济地位人群与其他群体之间仍存在明显数字鸿沟。年轻人，受教育程度和收入水平较高、具备数字接入条件、更频繁使用 eHealth 以及对 eHealth 持更积极态度者，与更高的 eHL 水平相关。本章强调了提升 eHL 与 CLD 知识水平的重要性，同时需要改善弱势群体的数字接入条件。研究识别出的 eHL 相关因素，为设计符合不同人群需求与偏好的个性化健康教育及 eHealth 干预提供了依据。

第五章综述了现有关于 CLD 数字健康教育（digital health education, DHE）的研究文献，并总结了 DHE 的传播媒介、教育内容、干预机制与结局指标。研究结果显示，该领域的发表数量呈增长趋势，但主要集中于高收入国家。网站与移动应用是最常用的传播媒介，教育内容主要聚焦于自我管理技能，而 DHE 的干预机制鲜有提及。大多数研究显示，DHE 能够提高患者对 CLD 的认知，改善健康、生活方式，以及心理和社会福祉，同时具有良好的实用性、可接受度与满意度。然而，仅有两项研究报告了成本效益指标，但都没有明确比较干预前后的成本。这表明 eHealth 在支持 CLD 健康教育方面具有潜力，但也揭示了文献中的重要空白，尤其需要加强对中低收入国家、干预机制及成本效益指标的关注。

基于荷兰基层保健的一项整群随机试验，**第六章**探讨了疾病意识与 eHL 是否影响数字吸入器对哮喘病人的干预效果，以及疾病意识，eHL 与人口学指标之间的关系。在该试验中，干预组使用具有自我监测与用药提醒功能的数字吸入器，而对照组则使用无反馈功能的被动监测吸入器。此前研究已证实，该数字干预项目能够有效改善哮喘控制与用药依从性。然而，本研究发现，疾病意识与 eHL 并未影响干预效果。这表明该用户友好型吸入器可能在不同疾病意识和 eHL 的患者中有相似效果，这也可能与样本整体 eHL 水平较高有关。此外，研究还发现，年轻人通常具备较高的 eHL。这些结果为评估其他影响因素提供了指导，用以识别 eHealth 干预获益最多或需要额外支持的群体，并强调了 eHealth 在不同人群中潜在的公平性效果。

第七章是论文总体讨论部分。通过整合不同情境与研究设计的研究结果，本论文识别了社区居民与医护人员中 CLD 相关的信念、认知，及多种行为挑战，评估了 eHL 及其相关因素，并探讨了 eHealth 在支持 CLD 健康教育与行为改变中的潜力。尽管 eHealth 已展示出积极效果，但数字接入受限、eHL 水平较低及社会经济地位较低的人群可能获益较少。这些结果强调了根据本地需求和情境调整健康教育策略的重要性，例如使用现有资源和简单易懂的本地语言，动员社区成员、领导者、教师、医护人员、政策制定者和设计者等关键利益相关方，并运用行为改变技术，以促进有效且可持续的行为改变。为缩小数字鸿沟并将 eHealth 潜力最大化，建议加强数字基础设施建设，鼓励终端用户参与 eHealth 的开发与评估，整合已有的行为改变技术，并为数字技能较低的人群提供技术支持。

Dankwoord

Four years ago, when I considered pursuing a PhD, I believed I would make it one day. Surprisingly, it has unfolded better than I expected, because of the people I have met, and the research I have done.

Foremost, I express my sincere gratitude to my supervisors: Prof. dr. Niels H. Chavannes, dr. Eline Meijer and dr. Marise J. Kasteleyn.

Niels, thank you for giving me the opportunity to pursue my PhD and your input on my manuscripts and career planning from a global perspective. Your words, “don’t be afraid of making mistakes”, shared in the quarterly meeting, still echo in my mind and will continue to guide me in my future work.

Eline and Marise, thank you for always giving detailed, constructive and inspiring feedback, while helping me a lot in refining my manuscripts, supporting my conference participation, seeking fundings, sharing relevant courses and references, and creating a workstyle in which I felt at ease. Every comment you left and the way you conduct research shaped who I am, motivated me to pursue a career in academia, and set a good example as supervisors, which I hope to pass on to my future students and collaborators.

To the “big sister” dr. Hongxia Shen, and my former supervisors dr. Rianne M.J.J van der Kleij, dr. Sofie Willems and Cynthia Hellensleben: Hongxia, thanks for supporting me through every key milestone of my PhD, from funding acquisition, PhD admission, to reviewing my conference abstract and thesis. Rianne, thanks for helping with my research proposal during my PhD application. The first year was challenging, but thanks to Rianne, Sofie and Cynthia, for accompanying me through the period of cultural shock, while completing my review project together. Thanks to Cynthia especially for inviting me to share my research experiences with Chinese students and Kyrgyz researchers.

To my paranymphs: Huohuo, thanks for sharing learning and career opportunities, helping with my projects, building connections in China and offering advice on dealing with anxiety; Atena, thanks for organizing engaging meetings and activities within NeLL and the PhD Committee, bringing interesting discussions. Thank you both for being my paranymphs and good luck with your PhD!

To my collaborators: Ms. Qing Zhang, Xiao, Yue, Liangqiuhe, thanks for helping with the data collection and ethical approval; Charlotte, Evelyn, Yoran, Job, Janwillem, Maamed, thanks for providing feedback and for your contributions to the project progress. These collaborations enabled me to stand higher, see further and think more deeply.

Rong Li: always my first consultant when I make big decisions. Having known each other for over 15 years, our friendship remained unchanged despite the distance between us and our different career paths. Jiangyi: cheers to our ten-year friendship. We both ended up in Europe, and continued the deep conversations, as we did back at university. Thank you!

Dr. Yan Liu, my mentor, statistical consultant and home fellow, thanks for your constant encouragement. Xiaoyue and Zhixun, thanks for your suggestions on managing PhD projects smoothly. Haijun, thanks for all the help you provided during my stay in Den Haag. Keyong and Mingwei, It's been great to have you as friends to travel with, celebrate my milestone, and share the PhD journey. Thanks to Ning, Yuan, Yinie, Junyao, Chuqi, Ling and all the friends that ate, sang, and went out together, these moments brought me beautiful memories.

Thanks to all the researchers I met, I never felt alone as we faced many of the same challenges in our field, despite our different backgrounds. My study participants, the building bricks of my thesis: behind the data were lively stories, filled with emotions and struggles that were not unfamiliar to me. I sincerely hope my work, in some way, can contribute to future policies and ultimately benefit them, even just a little. Living in the Netherlands also allowed me to meet and talk to minorities and migrants. Their stories and struggles, motivated me to hope that one day I would be able to speak for them, for example, on migrants' health.

Thanks to my guidance committee Maria and Padmini for providing critical suggestions on my PhD trajectory.

Thanks to the China Scholarship Council, Leiden University Medical Center for providing funding for my living and learning opportunities.

My mom, sister, and aunts, thanks for always supporting me from the other side of the phone. My dear dad, grandma and grandpa, how I wish I could still tell you everything I achieved and you would have been very proud. I always miss you, love you, no matter how far I go.

Finally, to the incoming Dr. Chao Sun: thank you for always adhering to your goals and never regretting every decision you made. Hope you keep going with your curiosity, perseverance and resilience in your future work and life!

Appendixes

Curriculum Vitae

Chao Sun was born on 22nd March, 1998 in Yiyang, Hunan Province, China. He studied at No. 1 High School of Taojiang County in Yiyang during 2012 to 2015. From September 2015 to June 2020, he finished his undergraduate studies in Preventive Medicine at School of Public Health, University of South China in Hengyang. In 2019, he undertook an internship at the Shenzhen Center for Disease Control and Prevention from January to May. During this period, he worked as a household survey investigator in a community health diagnosis project jointly organized by the local health committee, public health specialists, and community leaders. This experience provided him with firsthand insights into the challenges of conducting large-scale, detailed surveys, and the importance of multisectoral collaboration in primary care, and contributed data to his bachelor's thesis on health literacy. From June to September, he completed a second internship at the First Affiliated Hospital of University of South China, where he assisted with clinical consultations, medical records writing and infectious disease reporting. This deepened his understanding of struggles faced by both clinical doctors and patients, and more importantly, the importance of humanistic care in medical practice.

At the end of 2019, he took the National Postgraduate Entrance Examination in China and was admitted to the School of Public Health at Wuhan University for his master education (two-year program) in September 2020. Under the supervision of Prof. Xiaodong Tan, he developed skills in quantitative analysis by using public datasets. Despite the impact of COVID-19 pandemic, he obtained his Master of Public Health degree In June 2022, and was awarded The Second-class Academic Scholarship and the title of Outstanding Graduate.

In October 2022, he started his PhD at the Department of Public Health and Primary Care, Leiden University Medical Center in the Netherlands, funded by the China Scholarship Council. Under the supervision of Prof. dr. Niels H. Chavannes, dr. Eline Meijer and dr. Marise J. Kasteleyn, his doctoral research focused on health education needs and behavioral challenges related to chronic lung disease, as well as the potential of eHealth. He has worked in international and multidisciplinary teams and used qualitative and quantitative data collected in Kyrgyzstan, China and the Netherlands. These research experiences have fostered his interest in medical anthropology and motivated him to pursue an academic career in global health and digital health.