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Understanding the lived experience of people in Malaysia with asthma and limited health literacy and developing an intervention to support them with asthma self-management

Hani Syahida Salim

Submitted for the degree of Doctor of Philosophy

The University of Edinburgh

2021
Declaration

I confirm that this thesis, presented for the degree of Doctor of Philosophy in Global Health,

i) has been composed entirely by myself,

ii) that the work contained herein is my own except where explicitly stated otherwise in the text, and

iii) that the work has not been submitted for any other degree or professional qualification.

Hani Syahida Salim
Abstract

Introduction: People living with asthma need the knowledge and ability to respond to the demands of managing their variable symptoms. Supported self-management (including the use of written asthma action plans) improves health outcomes and reduces attacks. However, limited health literacy makes self-management difficult, which is especially challenging in low-to-middle-income countries (LMICs), where limited health literacy is prevalent. Tailored interventions, potentially including the use of mobile applications (apps), are needed to enable people with limited health literacy to realise the benefits of supported asthma self-management.

Aims and objectives: I aimed to

1. Systematically search for and synthesise evidence of clinical effectiveness of asthma self-management interventions targeted at people with limited health literacy and to identify strategies associated with effective programmes.

2. Explore experiences of living with asthma among people with limited health literacy in Malaysia, to understand the role of health literacy in influencing self-management decisions, the barriers to using evidence-based action plans, and how self-management can be supported.

3. Identify how to design an intervention underpinned by a theory of change.

4. Develop and refine a prototype asthma self-management app tailored to the needs of people with limited health literacy, optimising user experiences.

Methods: Using the Six essential Steps in Quality Intervention Development (6SQuID) model, the programme of work consisted of the following:

1. Following Cochrane methodology, I systematically searched ten databases using a Population, Intervention, Comparison, Outcome and Setting (PICOS) search strategy. Selection of papers, extraction of data and quality assessment (using the Cochrane Risk of Bias tool) were duplicated. The primary outcomes
were clinical (asthma control) and implementation (adoption/adherence to intervention). Analysis was narrative, due to the heterogeneity of studies.

2. I adapted an arts-based qualitative methodology, Photovoice. The study was conducted in four stages: 1: Initial in-depth interviews, 2: Photo-training and photo-taking activity, 3: Photo-interviews, 4: A photo-exhibition. I purposively sampled adults with asthma and limited health literacy from four primary healthcare clinics in a district of central Malaysia. Interviews were audio-recorded, transcribed verbatim, translated and analysed using two approaches:

i) Narrative exploration of the experience of living with asthma among people with limited health literacy in Malaysia; and

ii) Framework analysis informed by Sørensen's health literacy framework.

Findings were interpreted in discussion within a multidisciplinary group.

3. With reference to the 6SQuID model, I used the study findings to design an intervention.

4. I adapted the Design Sprint method to an online format that took place over five days. Stakeholders provided insights on self-management issues (Stage 1), which informed the development of the prototype (Stages 2 to 4). Participants with asthma and limited health literacy tested the prototype and provided qualitative feedback, including a ‘thinking-aloud’ process triangulated with screen recordings of app browsing activities (Stage 5). Interviews were audio-recorded, translated and analysed thematically to identify utility and usability issues.

Results:

1. I screened 4,318 titles and abstracts, reviewed 52 full-text studies, and included five studies. The risk of bias was low in one and high in the other four studies. Clinical outcomes were reported in two studies, both at high risk of bias. None reported uptake or adherence as an outcome of the intervention.
Behavioural change strategies typically focused on improving an individual’s psychological and physical capacity to enact behaviour (e.g., targeting asthma-related knowledge or comprehension). Less than half of the interventions used specific self-management strategies (e.g., written asthma action plans) tailored to limited health literacy status. A range of innovative approaches was used to provide education.

2. Twenty-six participants provided interviews; eight also completed the Photovoice activities.

i) The concept of autonomy was the primary lens that pulled the data together. Through the lens of autonomy, three themes were identified: asthma as a life story, reclaiming identity in the network of everyday relationships, and redefining interactions with the health system and environment.

ii) Health literacy was identified as a process of negotiating medical narratives and social practice. Participants with limited health literacy used various sources (e.g., social media) to access information about asthma and self-management but typically lacked appraisal skills. Doctor–patient communication had a pivotal role in helping patients understand asthma, though written action plans were rarely provided. Self-management decisions were influenced by socio-cultural norms, experiential knowledge and available social support. Specific challenges and recommendations in the use of action plans were identified.

3. Building on the previous literature, the systematic review and the qualitative study, I used Steps 1 to 4 of the 6SQuID model to define my intervention development.

4. Stakeholder discussions identified multi-level challenges. Five participants tested the prototype and described how the app influenced or could support self-management (utility): offering information, providing access to an asthma action plan, supporting medication adherence, and behaviour change. Specific usability issues addressed navigation, comprehension and layout.
Conclusion: People with asthma experience challenges in coping with the variable symptoms of acute asthma. In the context of people with limited health literacy, understanding asthma and making decisions about self-management were heavily influenced by societal norms; therefore, interventions require a whole-system approach. Mobile technology may be an appropriate medium for delivering tailored self-management support at an individual level. Future studies are needed to test the feasibility of the prototype intervention in clinical practice.
Lay Summary

What is asthma, and why is self-management important for people with asthma?
Asthma is a lung condition that causes occasional breathing difficulties. There is no cure for asthma; nevertheless, effective strategies can control the symptoms. One such strategy is a written asthma action plan, which can support self-management. An action plan is a set of steps agreed upon by both the patient and their healthcare professional for recognising health decline and the best course of action.

What is health literacy, and why is there a problem?
Health literacy is a set of knowledge and abilities that enable people to make decisions about their health and follow treatment instructions for their own and the community’s benefit. Limited health literacy skills are common globally but especially in low-to-middle-income countries (LMICs), so that understanding how to manage asthma and using tools such as action plans may be difficult. However, people with limited health literacy may benefit from tailored support, potentially via technology, in managing their asthma.

Aims of this PhD:
To learn about people living with asthma who have limited health literacy by asking
- What previous interventions have been described and tested?
- What are the lived experiences of people living with asthma who have low health literacy in Malaysia?
To build on these findings to develop asthma self-management support targeted at people with limited health literacy, I sought to
- Identify potential interventions that could potentially improve asthma control
- Work with stakeholders to develop a prototype mobile application (app).
How did I achieve my aims, and what I have learned?

Firstly, I searched for existing literature on asthma self-management interventions aimed at people with limited health literacy and found five studies that matched, though they were generally of poor quality, so I could not draw any clear conclusions on the usefulness of the interventions. I learned that there was a need to understand the barriers to good asthma self-management and to develop better tools to support people living with asthma.

Next, I interviewed 26 people from Malaysia with limited health literacy about what it was like to live with asthma. Eight of the participants took part in Photovoice. This is an adapted arts-based approach that encourages people to take photographs of significant aspects of their day-to-day lives or issues that matter to them. I then interviewed them about the photographs they had taken. I discovered how the participants gained the confidence they needed as individuals to cope with asthma. Understanding of asthma was influenced by social norms, whereas self-management decisions were based on experiences and what was practical in the participants’ context. However, I realised that asthma action plans were rarely provided or discussed during asthma follow-up consultations, a gap that I could bridge in the next stage of my PhD.

It was clear from what I had learned that interventions could be targeted at several levels and an intervention could include more than one component. Therefore, for this PhD, I decided to focus on developing a mobile app for people with asthma to support self-management, which would include several components. In an online Design Sprint workshop, I worked with asthma patients and experts to develop a prototype app that delivered several components, which we refined based on the participants’ feedback.

How did I share the findings, and how will this PhD work help people living with asthma?
I shared my findings through formal and informal platforms (e.g., social media). Additionally, I accompanied a patient at a small-scale photography exhibition to create a platform for discussion with attendees, including key decision-makers.

This PhD has provided insights into living with asthma and limited health literacy in Malaysia. I have learned about the influence of societal norms and people’s experiences in health decision making and recognise that ultimately change will necessitate a multi-level approach. I developed a solution at the individual level to raise asthma awareness and support empowerment and self-management abilities through a mobile app. Further study is needed to explore the practicality of using this intervention in patients’ daily lives.
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Contributions to science

Peer-reviewed publications from this PhD


Other publications related to asthma and/or health literacy


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# Abbreviation

<table>
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<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>6SQuID</td>
<td>Six essential Steps for Quality Intervention Development</td>
</tr>
<tr>
<td>ACCORD</td>
<td>Academic and Clinical Central Office for Research and Development</td>
</tr>
<tr>
<td>ACQ</td>
<td>Asthma Control Questionnaire</td>
</tr>
<tr>
<td>ACT</td>
<td>Asthma Control Test</td>
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<tr>
<td>AUKCAR</td>
<td>Asthma UK Centre for Applied Research</td>
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<tr>
<td>BCW</td>
<td>Behaviour Change Wheel</td>
</tr>
<tr>
<td>COM-B</td>
<td>Capability, Opportunity, Motivation-Behaviour</td>
</tr>
<tr>
<td>COPD</td>
<td>Chronic Obstructive Pulmonary Disease</td>
</tr>
<tr>
<td>DALYs</td>
<td>Disability-Adjusted Life Years</td>
</tr>
<tr>
<td>EPOC</td>
<td>Effective Practice and Organisation of Care</td>
</tr>
<tr>
<td>FEV1</td>
<td>Forced expiratory volume in one second</td>
</tr>
<tr>
<td>FVC</td>
<td>Forced vital capacity</td>
</tr>
<tr>
<td>GBP</td>
<td>Great British Pound</td>
</tr>
<tr>
<td>GINA</td>
<td>Global Initiative for Asthma</td>
</tr>
<tr>
<td>GRADE</td>
<td>Grading of Recommendations Assessment Development and Evaluation</td>
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<tr>
<td>HeLD</td>
<td>Health Literacy in Dentistry</td>
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<tr>
<td>HLS</td>
<td>Health Literacy Scale</td>
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<tr>
<td>HLS-SF</td>
<td>Health Literacy Scale-Short Form</td>
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<tr>
<td>ICS</td>
<td>Inhaled corticosteroid</td>
</tr>
<tr>
<td>LILACS</td>
<td>Latin American Interventions and Caribbean Health Science Literature Database</td>
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<tr>
<td>LMIC</td>
<td>Low-to-middle-income country</td>
</tr>
<tr>
<td>MOH</td>
<td>Ministry of Health</td>
</tr>
<tr>
<td>MRC</td>
<td>UK Medical Research Council</td>
</tr>
<tr>
<td>MYR</td>
<td>Malaysian Ringgit</td>
</tr>
<tr>
<td>NIHR</td>
<td>National Institute of Health Research</td>
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<tr>
<td>NMRR</td>
<td>National Medical Research Register</td>
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<tr>
<td>NVS</td>
<td>Newest Vital Signs</td>
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<tr>
<td>PEF</td>
<td>peak expiratory flow</td>
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<tr>
<td>PEFR</td>
<td>peak expiratory flow rate</td>
</tr>
<tr>
<td>PICOS</td>
<td>Population, Intervention, Comparison, Outcome and Setting</td>
</tr>
<tr>
<td>PPI</td>
<td>Patient and Public Involvement</td>
</tr>
<tr>
<td>PRECEDE</td>
<td>Predisposing, Reinforcing and Enabling Constructs in Educational/Environmental Diagnosis and Evaluation</td>
</tr>
<tr>
<td>PRISMS</td>
<td>Practical Review of Self-Management Support</td>
</tr>
<tr>
<td>PROCEED</td>
<td>Policy, Regulatory, and Organisational Constructs in Educational and Environmental Development</td>
</tr>
<tr>
<td>RCT</td>
<td>Randomised Controlled Trial</td>
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<tr>
<td>REALM</td>
<td>Rapid Estimate of Adult Literacy in Medicine</td>
</tr>
<tr>
<td>RESPIRE</td>
<td>NIHR Respiratory Global Health Unit</td>
</tr>
<tr>
<td>SABAs</td>
<td>short-acting beta-2 agonists</td>
</tr>
<tr>
<td>SCT</td>
<td>Social Cognitive Theory</td>
</tr>
<tr>
<td>SDI</td>
<td>Socio-Demographic Index</td>
</tr>
<tr>
<td>sTOFHLA</td>
<td>Short Test of Functional Health Literacy in Adults</td>
</tr>
<tr>
<td>TIDieR</td>
<td>Template for Intervention Description and Replication</td>
</tr>
<tr>
<td>TPB</td>
<td>Theory of Planned Behaviour</td>
</tr>
<tr>
<td>UNESCO</td>
<td>The United Nations Education, Science and Culture Organization</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
<tr>
<td>WHO ICTRP</td>
<td>World Health Organization International Clinical Trials Registry Platform</td>
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</tbody>
</table>
Chapter 1  Preliminary overview of the thesis

This chapter describes the structure of this thesis based on the aims and objectives that are outlined in more detail in Chapter 3. First, I describe RESPIRE, a National Institute of Health Research (NIHR) Respiratory Global Health Unit, which is the context for this RESPIRE-funded PhD. After an overview of the thesis, I provide a brief description of the overall role of Patient and Public Involvement (PPI) in this PhD.

1.1 RESPIRE: NIHR Global Health Respiratory Unit

RESPIRE is a Global Health Research Unit focusing on respiratory health in Asia (https://www.ed.ac.uk/usher/respire). It is funded by the National Institute of Health Research (NIHR). The unit is based at the University of Edinburgh and works in partnership with organisations in Bangladesh, India, Malaysia (Figure 1a) and Pakistan. RESPIRE’s vision is to reduce the impact and number of deaths from respiratory diseases in Asia in two programmes: i) Programme 1: acute lower respiratory tract infectious disorders, and ii) Programme 2: chronic respiratory conditions. Three cross-cutting platforms support these two research programmes:

i) Platform I: Stakeholder Engagement and Governance;

ii) Platform II: Training and Capacity Development; and

iii) Platform III: Methodology and Data Science.

Under Platform II, RESPIRE supports PhD studentship in all partner countries to undertake innovative research that is not only robust in methodology but also responsive and relevant to local needs.

1.1.1 RESPIRE in Malaysia

In Malaysia, the RESPIRE collaborations include two Malaysian institutions, the University of Malaya and Universiti Putra Malaysia, of which I am a member of Universiti Putra Malaysia. In one of the projects, the two institutions worked on an overarching programme of work in developing and evaluating interventions at patient and practice level to improve asthma care under RESPIRE programme 2 in the Klang District.
The Klang District is the capital of the Selangor State and one of its nine districts (Figure 1b). Selangor is one of the 13 states of Malaysia, with a population close to 5.5 million (making it the most populous state in Malaysia). The socioeconomic position of the population in Klang is generally low- to middle-income, which aligns with the NIHR’s focus on supporting socio-economically vulnerable populations in countries.

**Figure 1 Malaysia and Klang District, in a geographical context.**

a. The map of Malaysia

![Map of Malaysia](https://commons.wikimedia.org/wiki/Main_Page)

b. The position of Klang District within the Selangor state

![Map of Selangor State](https://commons.wikimedia.org/wiki/Main_Page)

Footnote: Reproduced with permission from Wikimedia Commons (https://commons.wikimedia.org/wiki/Main_Page) under the terms of Creative Commons Attribution Licence (http://creativecommons.org/licenses/by/4.0).
Two strands of projects were under RESPIRE’s programme of work in Klang: i) Klang Asthma Cohort; and ii) HEAL Asthma, both based in Klang District in central Malaysia. The Klang Asthma Cohort database is one of the research outputs of RESPIRE (NIHR Global Health research unit on respiratory health) in Malaysia. The database contains 1,280 people with asthma who were recruited from primary healthcare clinics in the Klang District. They have given consent to be contacted with invitations to participate in asthma-related research.

HEAL Asthma projects involved a broad quality improvement initiative, in which the projects involved the following:

i) Qualitative study to explore healthcare professionals’ views on and experiences of delivering asthma self-management and asthma care to patients; and

ii) Quasi-experimental pre-post study to determine the effectiveness of a pictorial asthma action plan to improve asthma control in adults.

Both studies aim to provide information that will facilitate the development of interventions to improve asthma management in the primary healthcare setting of Klang District Health.

Nested within HEAL Asthma (Figure 2), I led a PhD project focusing on the specific needs of people with limited health literacy. The overarching aim for this PhD programme of work was to understand the lived experience of people with asthma and limited health literacy and develop an intervention to support them with asthma self-management. I designed and carried out the projects for this PhD programme of work, supported by research resources and expertise from both the University of Edinburgh and Universiti Putra Malaysia.
1.2 Research environment and available expertise

As a RESPIRE PhD, this programme of work benefits from joint supervision between the University of Edinburgh (Professor Dr Hilary Pinnock and Dr Ingrid Young) and Universiti Putra Malaysia (Professor Dr Sazlina Shariff-Ghazali and Professor Dr Lee Ping Yein). Professor Pinnock is an expert in supported asthma self-management and implementation research, and Dr Young is an expert in health literacy, social science and creative qualitative methods. Professor Dr Sazlina Shariff-Ghazali is an expert in chronic disease management, patient empowerment and qualitative research methodology. Professor Dr Lee Ping Yein is an expert in asthma management, implementation research and shared decision making. My supervisions were undertaken jointly with monthly teleconferences supplemented by three or four face-to-face meetings each year.

I spent time in Edinburgh to benefit from the expertise and resources of the Usher Institute, Edinburgh. The centre offers an ongoing qualitative and
quantitative training programme involving social scientists, clinicians, epidemiologists, trialists and statisticians. These programmes are delivered via, among others, Master’s of Public Health Courses, Institute of Academic Development Courses and Edinburgh Clinical Research Facility Courses. In addition, RESPIRE has ongoing research-related programmes, including research data management webinars, in collaboration with other NIHR Global Health Research Units in the UK.

The Usher Institute at the University of Edinburgh provides a full range of support services (e.g., library facilities, computing support and cloud data storage) and office space. Likewise, the Universiti Putra Malaysia offers support facilities such as library, computing, data storage facilities (hardcopy and digital) and workspace.

1.3 Overview of this PhD

The high burden of limited health literacy among people with asthma in the Klang District in Malaysia calls for a tailored intervention to promote supported asthma self-management in the primary care setting [1]. Details about Malaysia and its health system, including provisions of asthma care in the primary care setting, are explained in section 2.4. This programme of work aimed to understand the lived experience of people with limited health literacy and develop an intervention to support them with asthma self-management through a pragmatic approach using Six Essential Steps for Quality Intervention Development (6SQuID; see Chapter 4). Table 1 outlines the projects in this programme of work, the corresponding chapter that describes the project, and the chapter’s content.
Table 1 The projects or content, the corresponding chapters and the summary of the chapters.

<table>
<thead>
<tr>
<th>Project or content</th>
<th>Chapter</th>
<th>Summary</th>
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</table>
| The overall structure, introduction and context of the thesis | Chapters 1–4 | • I outline the structure of this thesis in Chapter 1.  
• I describe in detail the context of this PhD in Chapter 2 (Introduction).  
• I provide the aims and objectives of the programme of work in Chapter 3.  
• Finally, I elaborate the framework which underpinned this PhD and its rationale in Chapter 4. |
| Systematic review | Chapter 5 | • I systematically searched for evidence of asthma self-management interventions aimed at individuals with limited health literacy.  
• I evaluated clinical effectiveness and identified the behaviour change strategies used in the included interventions associated with effective programmes. |
| Adapted Photovoice study | Chapter 6 | • I used adapted Photovoice methods (adapted from Photovoice) to explore subjective experiences of living with asthma among people with limited health literacy in Malaysia.  
• I used narrative analysis of in-depth interviews and photographs to understand people’s experiences of living with asthma. |
| | Chapter 7 | • I employed framework analysis (using the health literacy framework) to explore the role of health literacy in understanding asthma and how it influences self-management decisions, and to identify barriers to supporting evidence-based self-management plans for people with low health literacy. |
| Theory of change: mechanism of impact | Chapter 8 | • I synthesised evidence from previous literatures and chapters to identify how to develop an intervention, illustrating the process systematically using the 6SQuiD model. |
| Design Sprint | Chapter 9 | • I describe the use of the Design Sprint method to integrate patients and health professionals in the process of developing and refining a prototype mobile app to support people with limited health literacy to live with their asthma. |
1.4 Patient and public involvement in the PhD

Patient and public involvement (PPI) in Malaysia is relatively new. However, I have learned and gained generous support from the Stakeholder Engagement and Governance platform within RESPIRE. During the initial phase of my research, PPI members in the UK collaborated in the documentation aspect of my studies, such as designing the information sheet and consent form. PPI in Malaysia was established in 2019 and has made significant contributions to my project and the dissemination of findings. Specific PPI contributions are discussed in Chapter 6 (qualitative study) and Chapter 9 (development and refining intervention).

1.5 Summary and next step

In this chapter, I have presented an outline of how this thesis is organised around the PhD objectives. The PhD programme received supervision, training and funding from the NIHR Global Health Research Unit RESPIRE at the University of Edinburgh and the local institution, Universiti Putra Malaysia. PPI was important in the PhD process, and details of patient and public contributions are explained in the relevant chapters. The next chapter introduces the context of the overall programme of work.
Chapter 2  Introduction

In this chapter, I describe the context for this thesis. Specifically, I discuss asthma, its management, and the importance of supported asthma self-management. Under the umbrella of supported asthma self-management, I narrow the focus to the challenge posed by limited health literacy and the importance of tailored support. I also consider the potential of technology to support asthma self-management among people with limited health literacy, and I touch on e-health literacy. Finally, I set the scene by describing Malaysia: its society, asthma care delivery within the health system, and the burden of limited health literacy.

2.1 Asthma: a global public health issue.

Asthma is a chronic inflammatory airway disease with symptoms that vary in duration and intensity, affecting an estimated 360 million people worldwide [2-4]. In 2017, the incidence of asthma was 43.12 million new cases per year (0.56%), with a global prevalence of 272.68 million cases (3.57%) [4]. Among susceptible individuals, airway hyperresponsiveness to various stimuli causes bronchoconstriction (narrowing of the airway). These reactions produce symptoms such as recurrent wheezing episodes, breathlessness, chest tightness, and coughing, especially at night and early in the morning [5].

Risk factors for asthma exacerbations include viral infections; household allergens such as house dust mites and cockroaches; humidity; tobacco smoking; outdoor airway pollutants such haze; exercise; stress; and high body mass index [3,5-7]. These triggers, particularly for those with uncontrolled asthma, may cause a flare-up of asthma, which at best is uncomfortable and inconvenient and can be fatal at worst. Globally, asthma is the second leading cause of Disability-Adjusted Life Years (DALYs), making up 0.9% of total all-cause DALYs, with 0.49 million deaths (rate: 0.006%) [4], particularly in regions with a low Socio-Demographic Index (SDI) [6]. SDI is a composite measure of income per capita, mean years of education, and total fertility rate [6]. Age-standardised rates of DALYs due to asthma in low- and middle-
Income countries (LMICs), particularly Oceania, Southeast Asia, the Caribbean and southern Sub-Saharan Africa, are high, reflecting these regions' low SDI [3]. Conversely, higher SDI is significantly correlated with lower asthma incidence and asthma mortality [4,6], which may suggest better access to health services, accurate diagnosis and improved treatments. Various international bodies, including the WHO, have recognised the importance of timely diagnosis, appropriate management and accessibility of health services to optimise asthma control and minimise morbidity and mortality [8].

2.1.1 Diagnosis and clinical management

Asthma is a clinical diagnosis based on a history of variable respiratory symptoms and evidence of variable expiratory airflow limitation [5]. To make an asthma diagnosis, the Global INitiative for Asthma (GINA) recommends that on at least one occasion, the forced expiratory volume in one second/forced vital capacity (FEV1/FVC) ratio should be below the lower limit of normal based on multi-ethnic reference equations [5]. Variability of expiratory airflow limitation can be tested with bronchodilator reversibility using spirometry or a peak expiratory flow (PEF) meter [5]. The goal of asthma management is to reduce the risk of attacks and control symptoms. GINA defined good symptom control as having asthma symptoms less than twice a week during the day and using reliever medication, e.g. Short-Acting Beta2-Agonist (SABA) less than twice a week in the absence of night symptoms and no limitation to activity due to asthma [5]. Comprehensive care involves achieving patients' goals and respecting treatment preferences, with collaboration between healthcare professionals and patients.

The mainstay of therapy for achieving best outcomes is inhaled corticosteroid (ICS) treatment. The recent GINA 2021 guideline reflects this in its recommendation for asthma management for adults [5]. Based on current evidence [9,10], short-acting beta-2 agonists (SABA) are no longer recommended as first-line therapy for asthma. In a fundamental change, GINA recommends that all patients with asthma be treated with ICS regularly (titrated
Recommended components of regular asthma reviews or follow-up consultations include re-assessment of diagnosis and preferences for treatment, stepwise approach to medication adjustment and review of the response to treatment.

2.1.2 The role of supported asthma self-management

Besides pharmacological treatment, asthma self-management is emphasised in all national and international guidelines [5,11,12]. Self-management is defined as ‘the tasks that individuals must undertake to live with one or more chronic conditions. These tasks include having the confidence to deal with medical management, role management and emotional management of their condition’ [13].

Asthma self-management tasks include being able to recognise deterioration of asthma symptoms and take action – essential in a condition which varies over time and in intensity. In the absence of healthcare professionals, individuals must determine which treatment to take and when, particularly in the event of an asthma exacerbation. Thus, asthma self-management tasks need to be recorded in a written format so that a person living with asthma has a tangible plan they can refer to in their daily lives. A written asthma action plan is jointly agreed upon and negotiated between a patient and a healthcare practitioner. It is a personalised plan that assists a patient with asthma to identify worsening asthma symptoms, provides instructions on how to use reliever and controller medications as asthma symptoms intensify, and advises when to seek medical attention. A written asthma action plan has different formats (often utilising traffic light colours), but the plan’s core components remain the same across all national and international guidelines. Figure 3 provides an example of a written asthma action plan used in Malaysia [12].

In addition, the asthma action plan is not static. It needs to be reviewed regularly and revised by the healthcare professional according to the patient’s asthma status. The literature on self-management interventions for long-term conditions was synthesised in the Practical Review of Self-Management...
Support (PRISMS) [14]. This meta-review highlights the factors healthcare professionals may consider when assisting people with long-term illnesses, including asthma [14]. There were 14 components derived in this review, though useful components will vary between different people at different times with different long-term conditions.

**Figure 3 Written asthma action plan.**

![Written asthma action plan](image)

Footnote: Reproduced with permission from the Academy of Science Malaysia [12].

The combination of process and components to ensure asthma self-management is carried out to enable desirable health outcomes is called supported asthma self-management [15,16]. Supported asthma self-management, including regular reviews by healthcare professionals and provision of a written asthma action plan, has been shown to be highly effective at reducing mortality and morbidity related to asthma [5,11,17]. In addition, the variability of asthma control highlights the importance of self-management, as a patient needs to be able to recognise when their condition is worsening and act on it.
Globally, research has shown that ownership of action plans is limited, with barriers to implementing self-management in routine clinical practice, including lack of time and resources (such as no immediate availability of an action plan [18]), mismatch of needs between professionals and patients [19] and limited skills and support for effective doctor–patient communication [20]. Implementation of self-management in routine practice can be a challenge in many healthcare settings. One particular challenge is the need to tailor support to people with potentially limited levels of health literacy.

2.1.3 Pictorial asthma action plan: an innovative approach as an alternative for a written asthma action plan

A pictorial asthma action plan is a novel strategy that can be used in place of a written asthma action plan. Prior work in developing a pictorial asthma action plan was initially done by Robert et al. [21], and there was interest in using a similar concept of a pictorial asthma action plan but one that would be culturally tailored to the local context through RESPIRE work in Malaysia. Although the validation of this tool was conducted in the United Kingdom and Malaysia, the pictorial asthma action plan needs further revision to include a current recommendation by the latest GINA guideline [5] and the Malaysian Clinical Practice Guideline for asthma management in adults [12,22].

The adaptation work for local use was carried out by HEAL Asthma, within RESPIRE, of which I was a member. The adaptation process was iterative, with adjustments made to the action plan based on feedback from experts and stakeholders. Stakeholders included the advisory panel of the study location’s clinic and asthma patients who had previously used a text-based action plan. In addition, one of the asthma patients was a member of the RESPIRE PPI group. A panel of four Malaysian adult asthma patients (in addition to the stakeholders who assisted with the initial development) and five healthcare professionals reviewed the pictorial asthma action plan. The patients with asthma were identified through the Klang Cohort database, while the healthcare professionals were chosen due to their varied experience with text-based asthma action plans and providing service within the Klang Cohort.
Three of the healthcare professionals were family physicians, while the remainder were primary care medical officers (doctors with no postgraduate training who work in primary care clinics under the supervision of specialist family physicians). The pictorial action plan was reviewed to determine its content validity. Content validation is a method that ensures that an instrument (checklist, questionnaire or scale) assesses the content area that it is supposed to measure [23]. The process involves a panel of subject matter experts rating the content of the culturally tailored pictorial asthma action plan. The panel was asked to comment on the accuracy, clarity, style and relevance of the plan to the local social context. Content validity was measured using the Content Validity Ratio (CVR), which is a linear transformation of a proportional level of agreement on how many experts within a panel had a similar rating agreement [23]. A score of at least 0.78 (range: 1 and -1) means that the content of the pictorial asthma action plan is considered valid and rated favourably by all the experts on the panel [24]. The CVR was 1.00 for all the items, except for the image presenting ‘wheeze’, which received a rating of 0.78 and was rated unclear by one of the panellists. The image was modified based on this feedback. A feasibility study of the paper-based pictorial asthma action plan, which was recently completed, showed promising results in terms of asthma outcomes. However, the qualitative component of the feasibility study highlighted the challenges of holding on to a paper-based plan (e.g., a participant misplacing their plan and not bringing the plan during a consultation).

The culturally and low-literacy tailored asthma action plan (Figure 4) comprises pictorial information that depicts different levels of asthma control reflected by pictures of asthma symptoms and use of reliever and controller medications, as well as the types of treatment advised by the patient’s doctor (e.g., adding medications, increasing dosages or seeking medical attention). The pictorial asthma action plan is available in Bahasa Malaysia (the national language) and English languages.
2.2 Health literacy and tailoring of support

The United Nations Education, Science and Culture Organization (UNESCO) is an organisation that has positioned itself as an international agency leader in literacy. In 1997, through the Hamburg Declaration on Adult Learning (under Resolution 11), UNESCO stated that literacy is an aspect of ‘the basic knowledge and skills needed by all in a rapidly changing world, as a fundamental human right. In every society, literacy is a necessary skill in itself and one of the foundations of other life skills. Literacy is also a catalyst for participation in social, cultural, political and economic activities and learning throughout life’ [25]. Most other definitions of general literacy encompass aspects of the ability to use reading, writing and numeracy skills to meet basic needs or function effectively and develop as an individual [26]. Over the years, the definition of literacy has expanded from individual skills to include population-level capabilities [25].
‘Health literacy’ covers literacy in the realm of health. The initial definition of health literacy included the ability to handle words and numbers specifically in a health context [27]. In the last two decades, a broader concept of health literacy has been accepted, which involves the ability to understand health instructions, simultaneously use a complex set of abilities, act upon written health information and communicate with healthcare personnel [28]. This evolution of the health literacy definition to cover a more comprehensive concept is discussed further in the next section.

2.2.1 What is health literacy?

Health literacy is a widely used concept with a range of definitions. The early, widely cited definitions of health literacy were from the World Health Organization (WHO), the American Medical Association and the Institute of Medicine (Table 2).

**Table 2 Health literacy definitions**

<table>
<thead>
<tr>
<th>Organisation/Scholar</th>
<th>Definition of health literacy</th>
</tr>
</thead>
<tbody>
<tr>
<td>The World Health Organization (1998) [29]</td>
<td>The cognitive and social skills that determine the motivation and ability of individuals to gain access to, understand and use information in ways that promote and maintain good health.</td>
</tr>
<tr>
<td>The American Medical Association (1999) [27]</td>
<td>The constellation of skills, including the ability to perform basic reading and numeral tasks, required to function in the healthcare environment.</td>
</tr>
<tr>
<td>The Institute of Medicine (2004) [30]</td>
<td>The individual’s capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.</td>
</tr>
<tr>
<td>Zarcadoolas, Pleasant and Greer (2005) [31,32]</td>
<td>The wide range of skills and competencies that people develop to seek out, comprehend, evaluate and use health information and concepts to make informed choices, reduce health risks and increase the quality of life.</td>
</tr>
<tr>
<td>Freedman et al. (2009) [33]</td>
<td>The degree to which individuals and groups can obtain, process, understand, evaluate and act upon information needed to make public health decisions that benefit the community.</td>
</tr>
</tbody>
</table>
The World Health Organization (2016) [34] Health literacy is essential for making informed decisions and empowering individuals and communities. It is based on inclusive and equitable access to high-quality education and lifelong learning. It is a visible result of health education as part of health promotion. Cultural and situational demands placed on people, organisations and society mediate health literacy. Individuals are not solely responsible; rather, all information providers are.

A shared characteristic of these definitions is the emphasis on an individual’s ability to make health decisions. However, it has been debated whether the definition of health literacy should emphasise an individual’s capacity and how those individuals use their sets of skills to interact with the demands of the health system [35]. Zarcadoolas, Pleasant and Greer covered these concepts in their 2005 definition of health literacy [31,32]. Freedman et al. in 2009 then argued that the definition should also cover public and societal engagement and added these to their definition [33]. In 2012, a systematic review conducted by Sørensen et al. synthesised 17 definitions of health literacy in the literature and formulated the definition of health literacy that I use in this thesis [36].

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Health literacy is linked to literacy and entails people’s knowledge, motivation and competencies to access, understand, appraise and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course.

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Based on this review, Sørensen et al. have proposed an integrated conceptual model of health literacy (Figure 5). The model combines the characteristics of a conceptual model detailing the primary elements of health literacy with those of a logical model outlining the proximal and distal factors that influence health literacy, including the pathway that connects health literacy to health outcomes [36]. The review proposed four domains of competencies of health literacy (access, understand, appraise and apply) and these were defined as below [36]:
• Access refers to the ability to seek, find and obtain health information.
• Understand refers to the ability to apprehend the health information that is accessed.
• Appraise describes the ability to interpret, filter, judge and evaluate the health information that has been accessed.
• Apply refers to the ability to convey and use the information to decide on the maintenance and improvement of health.

These domains influence each other in a process-like manner, and this process (Figure 5) generates knowledge and skills which enable a person to navigate three components of the health continuum: healthcare, disease prevention and health promotion [36]. The position of the four components of the health continuum in this model signifies a shift in the emphasis of health literacy from individual health to a population or public health perspective [36].

**Figure 5 Integrated model of health literacy.**

![Diagram](image)

Footnote: Reproduced with permission from BioMed Central under the terms of Creative Commons Attribution Licence ([http://creativecommons.org/licenses/by/2.0](http://creativecommons.org/licenses/by/2.0)) [36].

Although there is wide variation in the definitions and conceptual models used in the literature, in their review, Sørensen et al. outline two conclusions derived from the analysis [36]. Firstly, health literacy is multidimensional, including the dimensions of functional, interactive and critical health literacy described by Nutbeam et al. [37] and the dimension of listening, verbal fluency, memory span and navigation described by Paasche-Orlow and Wolf [38]. Secondly, all
conceptual models used in the literature have emphasised that the key aspect of health literacy is not just focused on an individual but also on system-level factors that affect individual levels of health literacy [36]. Furthermore, the paradigm of health literacy is not static, involving processes that have evolved [36]. This concept echoes the recent WHO position (Table 2) on what health literacy entails not just for individuals but also for information providers (e.g., government, health systems and society) and information types spanning from oral to print to digital [34]. With the increased use of technology, for example, the concept of e-health literacy was conceptualised [39]. I consider this in Section 2.3 when examining the role of technology in supporting asthma self-management.

2.2.2 Measuring health literacy

In this PhD, I use a locally validated tool available in Malay (the national language of Malaysia) to measure health literacy levels throughout my work: the Health Literacy Scale (HLS). The original tool, HLS-EU-Q47, was developed to generate data on health literacy across Europe through the European Health Literacy Project (HLS-EU) [36,40]. The tool measures health literacy in three domains: healthcare, disease prevention and health promotion [36,40]. It assesses the degree of ability to access, understand, appraise and apply health information, and it measures the respondents’ ability to manage their disease when they are ill, manage themselves when they are at risk of a specific condition and manage their health to ensure longevity [36,40]. The health literacy meaning that underpins the development of HLS-EU emphasises that health literacy is a set of evolving competencies achieved through ongoing health education, either formal or informal [36,40]. Since then, HLS-EU-Q47 has been validated in Asian populations through the collaboration of the Asian Health Literacy Association in Vietnam, Malaysia, Taiwan, Kazakhstan and Indonesia [41,42].

The HLS contains 47 items that measure health literacy [36,40]. Each item’s perceived difficulty is rated on a 4-point Likert scale (1 = very difficult, 2 = difficult, 3 = easy, and 4 = very easy). The raw scores of the 47 items of the
HLS-EU-Q47 are used to generate an ‘Index’ with defined levels for dichotomised categories of ‘limited’ or ‘adequate’ health literacy levels [40]. Limited health literacy is defined as an Index of <33 points [40]. According to an expert assessment of the health literacy scores, scores above this threshold were associated with an increased likelihood of a person successfully pursuing their health interest [40]. The tool was translated into Malay and adjudged reliable with Cronbach $\alpha$ of 0.96 [43]. In Malaysia, experienced public health researchers pre-tested the questionnaire for readability and understandability, and the content was verified to reflect cultural perspectives [43].

A scoping review on the use of health literacy tools in Malaysia revealed that only four tools had been validated and translated for local use: Newest Vital Signs (NVS), HLS-Asia-Q47 (the tool used in the study), HLS-SF12 (the short version of HLS-EU-Q47, which was not available when I was planning this study) and HeLD-14 (Health Literacy in Dentistry) [44]. The use of NVS was inappropriate, as it requires participants to address six questions on reading an ice-cream nutrition label, a measurement of reading, comprehension and numeracy that does not reflect local practice and culture [45]. HLS-Asia-Q47 was a more holistic option, which had been used to measure health literacy among people with diabetes [46].

Limited health literacy is mediated by a variety of factors. Socio-demographic characteristics, such as income, education levels, social support and employment, are known to mediate limited health literacy among people with asthma [47,48]. Other factors include ethnicity, cultural background and language [48]. According to earlier literature, socially disadvantaged populations are disproportionately burdened by limited health literacy, which impacts their health [47,48]. However, such understanding has evolved, and recent literature has emphasised limited health literacy as a marker of broader life circumstances, such as limited access to education, limited language competence, and learning disabilities [49,50].
2.2.3 **Impact of limited health literacy on health outcomes and self-management decisions**

There is overwhelming evidence that improving asthma knowledge about health improves health literacy [51,52]. To date, the relationship between limited health literacy and asthma outcomes is less clear [1,52], although limited health literacy has been shown to lead to poorer health outcomes [53] in more common conditions such as diabetes [54] and heart problems [55]. A review identifies how health literacy impacts health outcomes in three ways [38]:

i) access to and utilisation of healthcare,

ii) patient–provider interactions, and

iii) self-care.

**Access to and utilisation of healthcare**

Limited health literacy may impede the effective use of health services and have an impact on health outcomes. For example, people will seek medical care if they believe they require it; those with limited health literacy may delay seeking medical attention due to a lack of understanding of the consequences of their asthma symptoms or due to downplaying their symptoms [38,56]. This delay may increase the utilisation of emergency care and hospitalisation for asthma exacerbations [38,56]. Furthermore, the complexity of the healthcare system (e.g., rules and regulations governing access to healthcare and/or disjointed health programmes for different conditions) makes it even more difficult for people with limited health literacy to participate in disease prevention and health promotion programmes [38].

**Patient–provider interactions**

Limited health literacy has an impact on the interactions between patients and healthcare providers. A lack of effective communication impedes information sharing, increasing the likelihood that a patient's needs will not be met, which may impact health outcomes [57,58]. Various barriers impede people with limited health literacy from actively participating in consultations. They may not always use communication strategies, such as establishing rapport and asking
clarifying questions, to address communication barriers and the gap in patient–doctor partnership [59,60]. The lack of active participation has been attributed to a lack of confidence and motivation and to perceived power differences between people with limited health literacy and health providers [56,59,61]. Some people may feel embarrassed during social interactions in healthcare settings because their limited health literacy is exposed during these interactions; for example, they may have difficulty understanding instructions or explanations [59,62]. Unmet needs during these consultations result in distrust of providers, pessimism about treatment, and lower satisfaction with medical care [59,63,64]. Moreover, healthcare professionals, who are often unaware of their patients’ limitations [65], complicate communication with patients by employing medical jargon, failing to listen, and displaying poor nonverbal communication skills [56,65].

**Self-care versus self-management**

Self-care is a term that is similar to self-management, and the two terms are sometimes used interchangeably. Self-care is defined as the processes people use to ensure that they, their children and their families stay fit and maintain good physical and mental health; to meet social and psychological needs; to prevent illness or accidents; to care for minor ailments and long-term conditions; and to engage in maintenance actions to ensure wellbeing after an acute illness or hospitalisation [66]. However, the main distinction between self-management and self-care is that self-management entails health professionals sharing clinical information in a way that patients understand and assisting them to do better what they have always done [67].

In the context of self-management, the term I use in this thesis, it has been shown that health literacy, and particularly the functional skills related to it, plays a crucial role in enabling supported self-management in asthma [67]. For example, difficulty reading is associated with improper use of inhalers and poor disease knowledge [68]. Poor numeracy skills are associated with increased emergency visits and hospitalisations among people with asthma [69]. Studies have also associated limited health literacy with erroneous health beliefs and
poor adherence to self-management activities [70,71]. Without health literacy skills, asthma self-management will be difficult [14,72], and patients are less likely to manage chronic conditions [51]. Patients need to be empowered to make adequate judgements on crucial aspects of self-management [73]. A component of supported self-management is a written action plan. However, the ability to use a written action plan requires a satisfactory health literacy level. In the United States, a study found that action plans were written at the literacy level of a sixth-grader (11-to-12 years old), which will challenge those without formal education or those who have only received primary school education [74]. The same study also found that graphics within an action plan needed to be improved to increase ease of use [74]. One study suggested that personal and community networks are potential resources to overcome barriers around limited health literacy in self-management [75].

**The broader context**

Recently, growing numbers of health literacy researchers have emphasised individual choice and social determinants in making health decisions and engaging with health services [76-78]. Individual choice and health decision making are reported to be governed by deeply embedded health beliefs, socio-cultural norms and culturally determined practices within a community [76], such as the decision to use complementary and alternative medicine [79]. Stigma directly impacts on the lived experiences of, and decisions made by, people living with asthma. Goffman (1963) defines stigma as an ‘attribute that was deeply discrediting and reduces the bearer from a whole person to a tainted, discounted one’ [80]. To date, qualitative studies exploring asthma, health literacy and the broader life circumstances that affect limited health literacy among multi-ethnic and multi-lingual Asian cultures are relatively limited. One of the aims of this PhD was to explore people’s life stories to understand their barriers and facilitators and how self-management can be supported among those with limited health literacy.
2.3 **The role of technology to support asthma self-management among people with limited health literacy**

Technology can address real-life challenges in healthcare by supporting behaviour change [81-83]. The ability of people with asthma to self-manage using a mobile application (app), for example, may ease the burden of chronic illness in cost-constrained health systems [83]. Until 2013, close to 200 asthma apps in English were available [84], although very few had features consistent with guideline recommendations for action plans. Most apps still focus on basic knowledge about asthma and diary functions [84].

Education, an asthma action plan and regular review are the essential components of effective self-management recommended in national and international guidelines [5,10]. The unique characteristics of mobile technology may help to tailor care for those with limited health literacy, by using creative illustrations and innovative video-based education as an alternative to wordy instructions. Potential alternative formats that could be included in a mobile app to tailor health literacy needs include a pictorial asthma action plan, interactive education, and reminders or prompts for regular review. However, it remains unclear what features are most effective to support asthma in a self-management app.

When considering the use of technology in healthcare, it is impossible to avoid the concept of e-health literacy, which is defined as the ‘ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained for addressing or solving a health problem’ [39]. Norman et al. described e-health literacy as a congregate of six basic skills (traditional literacy, health literacy, information literacy, scientific literacy, media literacy and computer literacy) [39]. Although one may not need to master the whole skillset to be able to use electronic health services or tools, a lack of any of these skills, especially health literacy, may reduce the benefits and values of electronic health services or tools to care for health. It is also increasingly recognised that the concept of health literacy is affected by multidimensional factors, including socio-economic, cultural and behavioural factors [85].
Two previous systematic reviews have looked at self-management interventions, including technologies for people with limited health literacy, in long-term health conditions [86,87]. However, neither of them specifically addressed supported self-management for people with limited health literacy in asthma. Moreover, there is limited evidence on the clinical effectiveness of asthma self-management interventions targeted at people with limited health literacy. This is a gap I address in this thesis.

2.4 Malaysia in context

2.4.1 A multi-cultural and multi-lingual country

Malaysia comprises 13 states and three federal territories. To date, Malaysia has a population of 32.7 million comprised of three major ethnic groups: Malay and Indigenous groups (69.6%), Chinese (22.6%) and Indian (6.8%) [88]. The Malays and the Indigenous groups, formally known as Bumiputera, or sons of the land, form the largest community in Malaysia. The official religion of Malaysia is Islam (61.3%), practised by the Malay. According to Article 11: Freedom of religion of Malaysia’s Constitution, the multi-ethnic population of Malaysia is given the freedom to practise religions of their choice, including Buddhism (19.8%), Christianity (9.2%) and Hinduism (6.3%) [89]. The official language in Malaysia is Bahasa Malaysia, also known as Malay, which is the native language of the Bumiputera. Other spoken languages include Mandarin and Tamil. English is taught formally in schools at all levels as the second language.

2.4.2 Asthma within the healthcare system

Malaysia has a dichotomous healthcare system comprising public and private systems. The Ministry of Health (MOH) oversees the public health system, including the primary healthcare professionals. The government heavily funds the public health sector through public taxation, while in the private sector, payment is often by fee for service or is covered by insurance policies. In the public health sector, services are free with co-payment ranging from MYR 1 (GBP 0.17) to MYR 5 (GBP 0.87) for outpatient services and MYR 3 (GBP
0.54) per day of admission [90]. The maximum MYR 5 (GBP 0.87) fee is for outpatient specialist consultation [90]. This charge covers the consultation, investigations and medicines. While the poor are not exempt from co-payment, a fee-waiver system ensures that everyone can access the public health service [91]. Government employees, school children and those aged 60 years and above receive these general services in the public primary care clinics for free [92].

The MOH provides primary, secondary and tertiary care for the population, with National Referral Centres having been established to provide specialised care and to support the care given by the primary care service [93]. Primary care is the most significant element of the healthcare system in Malaysia. Post-independence healthcare reformation saw the separation of general outpatient clinics from the hospital and the relocation of this service into the community.

A typical primary healthcare clinic consists of a family medicine specialist, medical officers, paramedics, nurses, and other allied health practitioners such as pharmacists, dietitians, nutritionists, physiotherapists, occupational therapists, laboratory and radiology technicians, and medical social workers [92]. The primary care clinics provide comprehensive care, including acute and chronic care, prevention and health promotion services, rehabilitation, palliative care services, maternal and child health, and dental care [92].

Asthma is given less priority than other long-term conditions in Malaysia, such as diabetes, with a lack of funding and attention from a health policy perspective [94]. The prevalence of adult asthma is 4.5%, and adult asthma is primarily prevalent among those with lower income, lower education, and the unemployed [95]. Studies have reported that adult patients’ asthma control remains inadequate and that they receive little or no education on their disease and treatment plans [96,97]. Despite the high prevalence of uncontrolled asthma, ICS use is low, with concerns about side effects and long-term dependency given as significant reasons for non-adherence to medication prescriptions [98]. In a study by Zainudin et al., more than half of the study population had never undergone a lung function test or heard of peak flow...
meters [98]. A third of patients with asthma have no scheduled follow-up, with evidence of reliance on unscheduled visits [98], and a report suggested that less than a third owned an action plan [99]. This trend highlights the tendency of patients with asthma in Malaysia to underplay their symptoms which may deter timely care.

2.4.3 Health disparity and the burden of health literacy in Malaysia

Health disparity in Malaysia is tied closely with the difference in regional development between the states in Malaysia and was, in some ways, influenced by its colonial history. Malaysia gained its independence in 1957, and prior to this, it had been a British Crown colony since 1867. Owing to its colonial heritage, (See Section 2.4.1), Malaysia is a multi-ethnic, multi-cultural and multireligious society resulting from the inflow of Chinese and Indian ethnicities mainly to the Peninsular and, to a lesser extent, the East Malaysia (Sabah and Sarawak, part of Borneo). The British brought them in to fulfil specific economic activities, i.e., ore miners and rubber estate workers. The active economic activities in Peninsular Malaysia brought in essential infrastructures such as roads and railways, which further enhanced the development of services such as schools and hospitals. Such progress is not the case in East Malaysia. East Malaysia makes up 60% of the landmass in Malaysia, but only 18% of its population. Owing to its mountainous landscape (a significant challenge to building an efficient transportation network) and scattered population, economic development has been held back by, for example, on-going reliance on river transportation. However, despite the growth and industrialisation of the peninsular states, a study has shown that health disparity among the poorer districts reflects an environment with fewer opportunities or facilities for a better quality of life for households [100]. The study also found that all districts, regardless of the average wealth of its population, have groups of people who are disadvantaged socio-economically and therefore susceptible to poorer health outcomes [100].
Despite being categorised as an upper-middle income country by the World Bank, the fruits of Malaysia’s economic progress are thus not dispersed evenly across the country. Such economic disparity has influenced development and access to core services such as education and health, leading to health disparities and potentially low health literacy.

Health literacy and the use of validated tools to determine health literacy level objectively is a relatively new paradigm in Malaysia. A population survey in Malaysia indicated that about 35% of the general population have limited health literacy [94]. Previous studies in Malaysia – which are disease-specific, focussing on diabetes, medical adherence and mental health – found that only 6%–20% of participants were deemed to have adequate health literacy depending on the tool used to measure the level of health literacy [44]. In a study completed prior to this PhD, I assessed health literacy among people with asthma at five primary care clinics in the Klang District and found that 60.5% of the participants had limited health literacy based on the validated Malaysian version of the HLS (HLS-Asia-Q47) [1]. In this study population, limited health literacy was associated with not receiving self-management education or an asthma action plan [1]. About half (50.9%) of the study population had uncontrolled asthma (based on Asthma Control Questionnaire, ACQ), with 87.3% self-rated themselves as having controlled asthma [1]. Klang is one of the most densely populated areas in Selangor and where this PhD programme of work took place. Future interventions should ensure the inclusion of strategies that meet the needs of people with limited health literacy – an aspect I explore and develop in this thesis.

2.5 Summary and next step

Despite being one of the world’s most common chronic respiratory diseases, asthma is less prioritised than other long-term conditions in Malaysia. Although asthma is not curable, it can be managed through evidence-based treatment and support. Effective asthma management can reduce the need for emergency care, improve asthma outcomes and reduce asthma-related morbidity, particularly if patients self-manage their condition.
A significant number of people living with asthma in Malaysia have limited health literacy and may find it difficult to self-manage their asthma. An evidence-based and culturally tailored intervention is needed to support self-management among people living with asthma who have limited health literacy. In the next chapter, I explain the aims and objectives of my research.
Chapter 3  Aims and objectives

3.1  Aim and objectives of this PhD

3.1.1  Aim
To understand the lived experience of people with asthma and limited health literacy and develop an intervention to support them with asthma self-management.

3.1.2  Objectives
i) To systematically search for and synthesise evidence of asthma self-management interventions aimed at individuals with limited health literacy:
   a. to evaluate the clinical effectiveness of these interventions, and
   b. to identify the behaviour change strategies used in the interventions associated with effective programmes.

ii) To explore subjective experiences of living with asthma among people with limited health literacy in Malaysia:
   a. to explore the experience of living with asthma,
   b. to explore the role of health literacy in understanding asthma and how it influences decisions about self-management, and
   c. to identify barriers to using evidence-based self-management plans among people with limited health literacy and to identify how the use of such plans can be supported.

iii) To design an intervention underpinned by a theory of change.

iv) To develop and refine a prototype asthma self-management app tailored to the needs of people with limited health literacy:
   a. to optimise user experience in prototype development by integrating patients and health professionals in the process,
   b. to model key aspects of the prototype and test utility and usability issues, and
   c. to refine and develop the prototype app.
Chapter 4  Framework for the thesis and rationale for key decisions

4.1 Introduction
This chapter describes the overarching framework underpinning this PhD. I chose the 6SQuID model to structure this PhD work. This framework informed the choice of methods and how these methods were combined to answer the research objectives in logical and evidence-based ways. Below, I outline the chosen study designs for the steps in the 6SQuID model, including the rationale for choosing these designs. Finally, I signpost each objective to the relevant chapters.

4.2 Overarching approach
This PhD work was centred on addressing the research problems and developing a solution that could be used in real-world practice. For this purpose, I used the 6SQuID model as an overarching framework to underpin the conduct of this programme of work.

4.2.1 An overview of the intervention development framework
In the early intervention development phase, designing and evaluating an intervention in a structured manner is critical, especially if it has more than one component. A framework or guidance to support such work is required to ensure that the intervention development phase has a strong rationale and is carried out systematically, to ensure completeness as well as cost and time effectiveness. There are several frameworks and guidance for the development of complex interventions [101-105].

I initially intended to use the UK Medical Research Council’s (MRC) guidance. This is a theory-based framework for developing complex interventions. The framework outlines four key stages: development, feasibility and piloting, evaluation, and implementation [101,102]. In the first stage, the framework outlines three broad stages of intervention development [101,102]: (1) Identifying the evidence base, (2) developing theory, and (3) modelling
process and outcomes. When I was conceptualising the PhD programme of work, I discovered that the MRC framework was primarily focused on evaluating interventions and did not provide explicit instructions on how to execute and achieve the steps of the framework’s development stage. However, in 2019, O’Cathain et al. published guidance on developing complex interventions based on the MRC framework [106]. This guidance was established using triangulation of evidence from three sources, including a review of literature on approaches to intervention development, interviews with experts and consensus methodology [106]. In the updated guidance, experts were defined as developers (people who had authored articles or books outlining various approaches to developing interventions and people who had developed interventions) and wider stakeholders (people who contribute to the broader intervention development community, e.g., directors of research funding committees and members of PPI panels) [106]. If I had started my PhD after this work had been published, this framework might have been my first choice.

I considered the PRECEDE-PROCEED framework, where PRECEED and PROCEED constructs are both acronyms [104]. PRECEDE stands for Predisposing, Reinforcing and Enabling Constructs in Educational/Environmental Diagnosis and Evaluation. It represents the process that precedes or leads up to an intervention. PROCEED stands for Policy, Regulatory and Organisational Constructs in Educational and Environmental Development and, as the name implies, describes how to carry out the intervention. It is used as a guide to approaching a health issue in the community and ensuring its success. This framework provides a practical structure and steps for developing a successful community-based intervention. However, because the steps are heavily data-driven, the entire process takes a long time and was beyond the scope of this PhD’s timeline.

I also considered intervention mapping. This framework provides a guide for the development of health education and promotion programmes. The intervention mapping process consists of five steps [103]:

[Chapter 4: Framework for the thesis]
i) developing a matrix of proximal programme objectives,  
ii) selecting theory-based intervention methods and practical strategies,  
iii) designing and organising a programme,  
iv) specifying adoption and implementation plans, and  
v) developing programme evaluation plans.

The framework is praised for its socio-ecological approach, stakeholder involvement, and incorporation of theories and evidence. The planning process is iterative rather than linear, although intervention mapping is proposed as a series of steps. Tasks and steps can be switched back and forth by intervention developers. However, the process is highly complex for a single researcher in a time-limited PhD project. It may also be difficult to operationalise, as each step builds on the previous ones, and failure to pay attention to one step can lead to errors and poor decisions.

Many of these guidelines and frameworks do not detail a practical approach to the intervention development process, or if they do, the steps are extensive, necessitating a longer timeline and being potentially challenging to fit into a PhD context. As a result of these considerations, I chose a framework with broader applicability to serve as the underpinning framework for this PhD: the 6SQuID model (Figure 6) [107].

**Figure 6 Using the 6SQuID model as an overall framework for this PhD.**
4.2.2 Overview and steps of the framework

In this study, I used the 6SQuID model as an overarching pragmatic framework for intervention development [108]. 6SQuID stands for six essential Steps for Quality Intervention Development. Published in 2016 [107], 6SQuID builds upon previous intervention development frameworks, such as the UK Medical Research Council’s guidance for developing and evaluating complex interventions [5], by integrating a set of practical steps which emphasises understanding the problem from the stakeholders at different levels [107]. 6SQuID was designed to respond to the realisation that, while there was a substantial body of research relevant to intervention evaluation, considerably less was available to inform the development of public health interventions. The framework promotes more effective use of scarce public resources by ensuring sufficient attention to methodical intervention formulation, suitable implementation, and rigorous evaluation. Co-creation with key stakeholders is crucial to the framework's intervention development process. There are examples of how the framework has been used, including to develop interventions to reduce sedentary behaviour at the workplace [109], active lifestyle among women with gestational diabetes [110] and improving adolescent mental health [111]. The six steps provide practical advice on how an intervention can be developed, as summarised in Table 3 [107].

Table 3 Outline of practical steps for each stage.

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Define and understand the problem and its causes.</td>
<td>This step emphasises several points. Most important is to define the research problem in depth and concisely. Thereafter, researchers must determine the burden (and distribution) of the problem in the population. The problems, their contributing causes, the impact on those directly/indirectly affected, and who is likely to benefit the least/most from an intervention must all be considered. Once this is decided, a literature review should be performed of existing solutions to the targeted problem and to understand why there is still a gap.</td>
</tr>
<tr>
<td>2. Clarify which causal or contextual factors are malleable and have the greatest scope for change.</td>
<td></td>
</tr>
</tbody>
</table>
Step 2 requires researchers to seek out the elements that shape the problems outlined in Step 1 and have the greatest potential for improvement. Because the causal pathways of complex problems can be diverse and interrelated, creating a diagram of the problems identified in Step 1 may assist in identifying the point(s) at which action is required and is likely to have the most significant impact.

3. **Identify how to bring about change: the change mechanism.**

After modifiable elements have been identified, Step 3 identifies how to accomplish the change. All interventions require a theoretical framework to underpin how change might be executed to reach the intended outcomes, often known as the ‘change mechanism’. The process that may produce effects may be directed towards individuals, groups or communities, or it may encompass all of these. Moreover, the planned goals may directly represent the ultimate goal, but they can also be short term or intermediate term, leading to a long-term or ultimate goal. Thus, a specified change mechanism, ideally with the engagement of key stakeholders, is crucial for developing the intervention.

4. **Identify how to deliver the change mechanism.**

Step 4 involves deciding how to best implement the change. It is beneficial to involve a wide range of stakeholders, ideally those with relevant experience, to guarantee effective implementation. One or more delivery alternatives may be necessary depending on the nature of the problems established in Step 1, the identified change mechanism devised in Step 3, and, most significantly, the target audience. The implementation plan necessitates the identification of conditions, resources, relevant risks and assumptions in order to assure the success of the work programme.

5. **Test and refine on a small scale.**

After determining the initial intervention plan, its feasibility must be tested and improvements made. Testing the intervention can aid in the clarification of fundamental and practical concerns such as acceptance, delivery organisations, who should deliver the intervention, and the required training.

6. **Collect sufficient evidence of effectiveness to justify rigorous evaluation/implementation.**

Finally, before allocating resources to a large-scale evaluation, sufficient evidence of effectiveness must be acquired. At this step, there must be evidence that the intervention achieves at least the short-term goal and does not have any unexpected repercussions. With limited resources, the most practical way to obtain evidence of effectiveness is through a before-and-after study, a survey or routinely collected data.
4.2.3 Study design

I used the 6SQuID model to structure a programme of work to develop and refine an intervention to support asthma self-management tailored to people with limited health literacy in Malaysia. Corresponding to the framework’s steps, I started the exploratory work with a systematic review examining the effectiveness of asthma self-management interventions tailored for people with limited health literacy (see Chapter 5). I sought to understand the experience of living with asthma among people with limited health literacy and decided to adapt an arts-based qualitative method, Photovoice, because the photographic method could potentially allow a comprehensive understanding of how people understand and experience illness. The adapted methodology also provides insight into how health literacy affects self-management decision-making and how evidence-based self-management practices could be enabled (See Chapters 6 and 7).

Chapter 8 describes how I used the 6SQuID model to describe the decisions underpinning the design and development of the intervention based on findings of previous literature, the systematic review and qualitative study. I concluded Step 4 of the 6SQuID model by proposing an asthma self-management mobile app aimed at people with limited health literacy. The intervention development was constructed through a co-production method, Design Sprint [112]. A Design Sprint method is a five-day, agile and innovative methodology. It brought together stakeholders, such as patients and healthcare professionals, to contribute in the development phase and in the testing for usability and utility of the prototype (Chapter 9). A refined app was developed, ready to be used for future feasibility testing.

4.3 Ethical approval

The qualitative phase of this PhD involved interviewing participants with asthma who received their care at various primary care clinics in the Klang District, Malaysia. I received ethical approval from the Medical Research and Ethics Committee of the Ministry of Health, Malaysia, and the study was listed on the National Medical Research Register (NMRR; ID: NMRR-18-2113-
42322; Appendix 1) and received sponsorship approval from the Academic and Clinical Central Office for Research and Development (ACCORD) at the University of Edinburgh (ID: AC18113; Appendix 2).

Subsequently, for the development and feasibility of the intervention, I received ethical approval from the Medical Research and Ethics Committee of the Ministry of Health, Malaysia (ID: NMRR-19-3609-52292; Appendix 3) and sponsorship approval for the development phase by ACCORD at the University of Edinburgh (ID: AC20011; Appendix 4). The initial face-to-face intervention design workshop involving stakeholders, such as patients and healthcare professionals, was planned in Malaysia in mid-March 2020. However, the global pandemic hit, and by March 2020, the Malaysian and UK governments put variable lockdown orders in place. As a result, I changed the format of the Design Sprint workshop from face-to-face to a remote meeting, and this change required an amendment of ethical approval from the Medical Research and Ethics Committee of the Ministry of Health, Malaysia. The amended protocol received ethical approval from the Medical Research and Ethics Committee of the Ministry of Health, Malaysia (ID: NMRR-19-3609-52292; Appendix 5).

4.4 How the PhD objectives are addressed and the structure of the thesis

Table 4 summarises the thesis objectives and maps them to their respective phases. The detailed methodology is presented in the respective chapters that follow.
### Table 4 List of objectives and the framework used.

<table>
<thead>
<tr>
<th>PhD Objectives</th>
<th>Methods</th>
<th>Summary of framework</th>
</tr>
</thead>
</table>
| **1** To systematically search and synthesise evidence of asthma self-management interventions aimed at individuals with limited health literacy:  
  a. to evaluate the clinical effectiveness of these interventions, and  
  b. to identify the behaviour change strategies used in the interventions associated with effective programmes. | Systematic review              | • Steps 1 and 2 of the 6SQuID model  
• Behaviour Change Wheel (BCW)  |
| **2** To explore subjective experiences of living with asthma among people with limited health literacy in Malaysia:  
  a. to explore the experience of living with asthma,  
  b. to explore the role of health literacy in understanding asthma and how it influences decisions about self-management, and  
  c. to identify barriers to using evidence-based self-management plans among people with limited health literacy and to identify how the use of such plans can be supported. | Adapted Photovoice study       | • Steps 1 and 2 of the 6SQuID model  
• Health literacy framework  |
| **3** To design an intervention underpinned by a theory of change.            | Theory of change: mechanism of impact | • Steps 3 and 4 of the 6SQuID model   |
To develop and refine a prototype asthma self-management app tailored to the needs of people with limited health literacy:

a. to optimise user experience in prototype development by integrating patients and health professionals in the process,
b. to model key aspects of the prototype and test utility and usability issues, and
c. to refine and develop the prototype app.

### 4.5 Summary and next step

In this chapter, I have given an overview and justification of the methodologies used in this programme of work. To explore the lived experiences of people living with asthma and develop an asthma self-management intervention tailored to the needs of those with limited health literacy, I used a pragmatic approach based mostly on qualitative methodologies. A systematic review gives a structured method to meet the initial research objectives of the thesis.

The next chapter describes the systematic review undertaken to synthesise existing evidence of asthma self-management interventions aimed at individuals with limited health literacy, to evaluate the clinical effectiveness of these interventions and identify the behaviour change components associated with effective programmes.
Chapter 5  Systematic review

This chapter reports the methodology and findings of a systematic review synthesising the evidence of the clinical impact of asthma self-management intervention targeted at people with limited health literacy and identifying the behaviour change strategies which lead to effective programmes. Figure 7 depicts the entire PhD programme of work, which is reported in this thesis using the 6SQuID model (Steps 1 to 4) [107]. The red circle refers to the part of the work that I discuss in this chapter.

![Figure 7 Using the 6SQuID model as an overall framework for this PhD.](image)

The review was registered with the PROSPERO database (registration number: CRD 42018118974). The work presented in this chapter has been presented at three conferences (Appendix 6) and published in two peer-reviewed journals (including the review protocol; Table 5). This chapter uses the initials of the co-authors in Table 5 to describe their contributions in the review process. In addition to my supervisors (HP, IY, PYL, SSG), I enlisted the help of SNR (a fellow PhD student) and KMcC (a health psychologist).
Table 5 Summary of the publications and list of co-authors.

<table>
<thead>
<tr>
<th>Publication Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>The systematic review protocol was published in NPJ Primary Care Respiratory Medicine (Appendix 7), and the manuscript was subsequently published in the Journal of Global Health (Appendix 8).</td>
</tr>
<tr>
<td>- Salim H (HS), Ramdzan SN (SNR), Shariff-Ghazali S (SSG), Lee PY (PYL), Young I (IY), McClatchey K (KMcC), Pinnock H (HP). A systematic review of interventions addressing limited health literacy to improve asthma self-management. J Glob Health. 2020; 10:010428.</td>
</tr>
</tbody>
</table>

5.1 Introduction

I decided to conduct a systematic review of interventions addressing limited health literacy to improve asthma self-management. Systematic reviews use a structured approach to identifying, understanding, analysing and summarising the evidence provided by previous research.

Previous reviews have not specifically addressed supported self-management for people with limited health literacy in asthma. A review by Sheridan et al. in 2011 included 38 studies, where 22 were randomised trials. Only three asthma-related interventions were part of this review, two of which reduced emergencies and hospital admissions [87], but the two studies were not randomised controlled trials (RCTs). A review by Schaffler et al. in 2018 included one asthma-related study in its review of self-management interventions among people from low socioeconomic groups, where fewer than half were in populations with limited health literacy [86]. Both reviews concluded that mixed-strategy interventions targeting three to four self-management skills (specifically including problem-solving) were more likely to be effective than single-component self-management interventions for people with limited health literacy. However, these reviews have limitations: the searches by Sheridan et al. were completed in 2011, and half the populations included in the more recent review by Schaffler et al. were defined by low income (on the assumption that these populations had limited health literacy) [86,87].

[Chapter 5: Systematic review]
5.2 Objectives of this systematic review

To systematically search and synthesise evidence of asthma self-management interventions aimed at individuals with limited health literacy:

a. to evaluate the clinical effectiveness of these interventions, and
b. to identify the behaviour change strategies used in the interventions associated with effective programmes.

5.3 Methodology

I conducted this systematic review using the Cochrane Handbook procedures for Systematic Reviews of Interventions [113].

5.3.1 Deviations from the published protocol

To be inclusive of data from LMICs, I planned to explore the African Index Medicus, Africa Portal Digital Library, Index Medicus for the Southeast Asia Region, IndMed, and the Latin American Interventions and Caribbean Health Science Literature Database (LILACS). However, in discussion with a librarian, I decided to omit these after a scoping exercise revealed a lack of controlled trials in these databases, and I considered it doubtful that any of these publications would fulfil my inclusion criteria.

I intended to use the Grading of Recommendations Assessment Development and Evaluation (GRADE) to assess the weight of evidence from the included studies’ reported results [114]. The outcomes of interest for this exercise were asthma control; FEV1 % predicted; and unscheduled care, such as visits to emergency departments (EDs), primary care practitioners and hospitalisations due to asthma exacerbations. However, there were too many missing data for GRADE to be applied (Table 6). For example, in terms of asthma control, the relative effect of the intervention is uncertain for several reasons. Two studies included asthma control as the outcomes [115,116]; however, both studies were at high risk of bias. In addition, both studies utilised different (validated) scales to quantify asthma control and found no difference between intervention and control [115]. One study, however, only reported this in the text and did
not mention it in the full data results [115]. Thus, I could not use the GRADE in relation to measuring the weight of evidence for all the included studies.
Table 6 Attempt to produce a GRADE table.

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Illustrative comparative risks* (95% Confidence Interval, CI)</th>
<th>Relative effect (95% CI)</th>
<th>No. of Participants (studies involved)</th>
<th>Quality of the evidence (GRADE)</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Assumed risk</td>
<td>Corresponding risk</td>
<td>Asthma self-management intervention</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Usual care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asthma control [115,116]</td>
<td>See comment</td>
<td>See comment</td>
<td>Not estimable</td>
<td>367 (2)</td>
<td>See comment</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>------------------------</td>
<td>---------------------------------------------------------------</td>
<td>---------------------------------------------------------------</td>
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<td></td>
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<tr>
<td></td>
<td>See comment</td>
<td>See comment</td>
<td>See comment</td>
<td>See comment</td>
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<tr>
<td></td>
<td>See comment</td>
<td>See comment</td>
<td>See comment</td>
<td>See comment</td>
<td></td>
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<tr>
<td></td>
<td>Not estimable</td>
<td>Not estimable</td>
<td>Not estimable</td>
<td>Not estimable</td>
<td></td>
</tr>
<tr>
<td></td>
<td>333 (1)</td>
<td>496 (3)</td>
<td>129 (1)</td>
<td>333 (1)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>See comment</td>
<td>See comment</td>
<td>See comment</td>
<td>See comment</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>The effect is uncertain.</td>
<td>The effect is uncertain.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>This study was at high risk of bias [115]. The effect between intervention and control groups is reported, but this is only reported in the text [115].</td>
<td>This study was at high risk of bias [117]. It did not report on the effect between intervention group and control but did report the effect between different health literacy level groups [117].</td>
<td></td>
</tr>
<tr>
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<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>The effect is uncertain.</td>
<td>The effect is uncertain.</td>
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</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>This study was at high risk of bias [115]. It reported the effect between intervention and control groups, but this is only reported in the text.</td>
<td>This study was at high risk of bias [115]. It reported the effect between intervention and control groups, but this is only reported in the text.</td>
<td></td>
</tr>
</tbody>
</table>

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5.3.2 Search terms and definitions

The systematic review was undertaken to assess the clinical effectiveness of asthma self-management interventions targeted at people with limited health literacy and to identify strategies associated with effective programmes. In consultation with a librarian, I selected the essential terms from my objectives to decide on the keywords.

Next, I defined the principal search terms used in this review (Table 7). However, upon completion of a preliminary scoping and in the process of defining the search terms, it was apparent that terms such as ‘health literacy’ varied between studies and only a few used validated tools to select a population with limited health literacy. Therefore, to avoid the risk of excluding potentially relevant studies because they had not used specific terms, I refined operational definitions to reflect components of the intervention. For example, I decided to choose asthma self-management interventions that included components of self-management as described in the taxonomy of self-management support by Pearce et al. [17]. Another example was the definition of populations with limited health literacy. I decided to include interventions in which at least 40% of participants had objectively determined limited health literacy or which concerned a population with published evidence of a high prevalence of limited health literacy, such as ethnic minorities [119], and to include any interventional designs which explicitly aimed to improve health literacy using techniques described by Sheridan et al. [87]. Last but not least, the populations in the included interventions were of any age with physician-diagnosed asthma and health outcomes based on the European Respiratory Society/American Thoracic Society (ERS/ATS) Task Force report [120].
### Table 7 Definitions of terms.

<table>
<thead>
<tr>
<th>Terms</th>
<th>Definition</th>
<th>Operational definitions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-management</td>
<td>The tasks that individuals must undertake to live with one or more chronic conditions. These tasks include having the confidence to deal with medical management, role management and emotional management of their conditions [13].</td>
<td>I included asthma self-management interventions including components described in the taxonomy of self-management support by Pearce et al. [17]:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>a) Direct components (delivered directly to patients and/or carers) such as education, action plans and practical support with adherence.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>b) Indirect components: health or social care professional level (delivered to individual health or social care professionals) such as equipment, feedback and review.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>c) Indirect components: delivered at an organisational level such as prompts using paper or electronic reminders.</td>
</tr>
</tbody>
</table>
Health literacy is linked to literacy and entails people’s knowledge, motivation and competencies to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course [36].

I included interventions that measured the health literacy level of the study population using a validated tool, and if 40% or more of the participants had limited health literacy; studied a population with published evidence of a high prevalence of limited health literacy. Examples were socioeconomically deprived populations, immigrants and ethnic minorities [119,121].

I also included any interventional designs which explicitly aimed to improve health literacy by using any of the following techniques described by Sheridan et al. [87]:

1) Presenting written information differently (e.g., essential information first)
2) Presenting numerical information differently (e.g., the highest number is better)
3) Using icons, symbols and graphs
4) Presenting information pitched at a lower literacy level (e.g., primary school comprehension)
5) Using videos
6) Providing literacy training for patients and physicians
7) Implementing comprehension skills to enable self-care

Severe asthma attacks
Deterioration of asthma control that requires urgent action on the part of the patient and physician to prevent a serious outcome, such as hospitalisation or death from asthma [120].

Relevant actions included commencing a course of oral steroids and emergency admission.

Footnotes: Reproduced with permission from Springer Nature for NPJ PCRM [118].
Table 8 PICOS table and operational definitions.

<table>
<thead>
<tr>
<th>PICOS</th>
<th>Descriptions and definitions</th>
<th>Operational definitions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population</td>
<td>Patients with physician-diagnosed asthma or their parents/carers.</td>
<td>Any age: children, adolescents, adults and/or the elderly</td>
</tr>
<tr>
<td>Intervention</td>
<td>Asthma self-management targeted at participants with limited health literacy levels, noting the authors’ definitions of health literacy.</td>
<td>See Table 7 for the definitions.</td>
</tr>
<tr>
<td>Comparator</td>
<td>Usual care or alternative interventions.</td>
<td>Alternative self-management strategies may include self-management interventions not targeting health literacy.</td>
</tr>
<tr>
<td>Outcomes</td>
<td><strong>Primary health outcomes</strong></td>
<td>Asthma control measured by a validated questionnaire such as the Asthma Control Questionnaire [122] or Asthma Control Test [123].</td>
</tr>
<tr>
<td></td>
<td>Based on the European Respiratory Society/American Thoracic Society (ERS/ATS) Task Force report [120], health outcomes were:</td>
<td>Asthma attacks were defined in line with the ERS/ATS definition of 'severe asthma exacerbations' (see Table 7).</td>
</tr>
<tr>
<td></td>
<td>- Current asthma control (e.g., control questionnaires)</td>
<td>Examples of adoption/adherence included the proportion of participants taking up the intervention who were provided with an action plan, or the frequency of usage of an action plan.</td>
</tr>
<tr>
<td></td>
<td>- Asthma attacks (e.g., number of severe attacks, steroid courses, emergency department visits, hospitalisations).</td>
<td>Secondary outcomes were intermediate measures known to reflect self-management skills or provide other evidence of impact.</td>
</tr>
<tr>
<td></td>
<td><strong>Primary implementation outcomes</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Adoption of the intervention</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Adherence to intervention</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Secondary outcomes</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Self-efficacy, activation, empowerment, health literacy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Improvement in knowledge and correct inhaler use</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Cost-effectiveness, fidelity and sustainability.</td>
<td></td>
</tr>
<tr>
<td>Setting</td>
<td>Any clinical or community-based setting in any country (developed or developing nations).</td>
<td></td>
</tr>
<tr>
<td>------------------</td>
<td>--------------------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Study design</td>
<td>Controlled experimental studies: Randomised controlled trials (RCTs), controlled clinical trials, controlled before-and-after studies and interrupted time-series designs.</td>
<td></td>
</tr>
<tr>
<td>Databases searched</td>
<td>MEDLINE; EMBASE; CINAHL Plus; PsycINFO; AMED; BNI; Cochrane Library: Database of Abstracts of Reviews of Effects, Cochrane Database of Systematic Reviews (CDSR) and Cochrane Central Register of Controlled Trials (CENTRAL); Web of Science Core Collection; ScienceDirect; Global Health.</td>
<td></td>
</tr>
</tbody>
</table>

Footnote: Reproduced with permission from Springer Nature for NPJ PCRM [118].
5.3.3 Search strategy

During the protocol development, I engaged with a librarian at the University of Edinburgh who is an expert in conducting systematic reviews to assist me in setting up criteria for my search strategy and refining my search using PICOS criteria.

I used Boolean logic to search for health literacy OR asthma OR self-management OR controlled trial in my search strategy. The search strategy used medical subject headings (MeSH; Appendix 9). Once the keywords were identified, the search terms were piloted, and the terms were refined using a single term or word combination.

Using PICOS criteria (Table 8), I searched ten electronic databases (MEDLINE; EMBASE; CINAHL Plus; PsycINFO; AMED; BNI; Cochrane Library: Database of Abstracts of Reviews of Effects, Cochrane Database of Systematic Reviews (CDSR) and Cochrane Central Register of Controlled Trials (CENTRAL); Web of Science Core Collection; ScienceDirect; Global Health). The initial search (January 1990 to June 2018) was updated in October 2019. Although the term health literacy was introduced in 1970 [124], the concept of asthma self-management was first recommended in asthma guidelines in 1990 [125].

I expected that the included studies would be implementation studies, which often employ a range of methodologies [126], and therefore RCTs, controlled before-and-after studies, quasi-experimental studies, interrupted time series and repeated measures were all included in the search criteria. Reviews, systematic reviews, meta-analyses, guidelines, surveys, abstracts, and study protocols were excluded, though published results were sought when a relevant protocol or abstract was identified. Although systematic reviews were not included, I searched the reference lists for other relevant studies and undertook forward citation for relevant studies. The results did not include editorials, opinion pieces, letters, case studies or audits. I contacted experts in the field to identify related trials. However, I did not perform manual searches,
since no journal(s) emerged as having a particular interest in this topic. There was no language restriction, though I did not find any non-English publications.

For unpublished and in-progress studies, I searched the World Health Organization International Clinical Trials Registry Platform (WHO ICTRP; www.who.int/ictrp) and the US National Institutes of Health Ongoing Trials Register (ClinicalTrials.gov; www.clinicaltrials.gov) for relevant trials.

5.3.4 Screening process
In an initial training process, the two reviewers (HS and SNR) screened a sample of 100 titles and abstracts. We compared the results and refined the inclusion and exclusion criteria, reaching a 100% agreement after two discussions. Title and abstract screening were then undertaken independently by the two reviewers.

Subsequently, we compared results, agreed on potentially relevant studies and obtained the full texts. Assessment of full text for eligibility was performed independently by both reviewers. Any uncertainties and discrepancies at all stages were remedied through discussion (including HP, IY, SGS or PYL as necessary).

A study with multiple publications (e.g., a protocol, trial findings, process evaluations, qualitative studies and translations) was treated as a single study, with references made to the different publications.

5.3.5 Data extraction
For the data extraction form (Appendix 10), I adapted the headings from the Effective Practice and Organisation of Care (EPOC) Good Practice data extraction form [127]. The headings include the following:

a. Population characteristics: ethnicity, age, socioeconomic status, health literacy level and tool used to determine health literacy level, asthma control, and geographical area and setting.
b. Descriptions of the interventions: Procedure, intervention and control components, mode of delivery and length of intervention, and tailoring to health literacy.

c. Outcomes: The primary health outcomes were current symptom control and risk of acute attacks, to reflect guideline recommendations [5, 120]. My primary implementation outcome was measures of adoption of the intervention. Definitions, methods of assessment and secondary outcomes are presented in Table 8. Secondary outcomes included intermediate self-management measures (e.g., knowledge improvement), health literacy outcomes, and impact indicators (e.g., cost effectiveness).

The form was piloted and later used by two reviewers (HS and SNR) independently to extract the data (Appendix 10). I communicated with the authors of the included papers to obtain any information that was missing from them. Authors were also contacted if conference abstracts which met the inclusion criteria were without publications. I did not include any abstract without a full paper publication.

5.3.6 Quality assessments

Risk of bias

I appraised the quality of the methodology of the included studies using the Cochrane Collaboration’s ‘Risk of Bias tool’ [113]. Each study was assessed on each of these biases: selection, performance, detection, attrition, reporting and other potential sources of bias [113]. The domains of bias and their descriptions are summarised in Table 9 [113].

Table 9 A summary of types of bias and the description of bias.

<table>
<thead>
<tr>
<th>Type of bias</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Selection bias</td>
<td>Descriptions of measures used to generate the allocation sequence in sufficient detail to produce comparable groups for assessment and concealment of such process.</td>
</tr>
<tr>
<td>Performance bias</td>
<td>Descriptions of the effective measures used to blind participants and health care providers from knowing about the intervention the participants received and the effectiveness of such strategy.</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Detection bias</td>
<td>Descriptions of measures used to blind outcome assessors, and effectiveness of such blinding.</td>
</tr>
<tr>
<td>Attrition bias</td>
<td>Descriptions of completeness of outcome data including attrition (lost to follow-up, withdrawn) and exclusions from the analysis.</td>
</tr>
<tr>
<td>Reporting bias</td>
<td>Systematic descriptions of differences between outcomes reported and protocol.</td>
</tr>
<tr>
<td>Other bias</td>
<td>Bias due to problems not covered elsewhere.</td>
</tr>
</tbody>
</table>

The risk of bias was categorised as ‘low’, ‘high’ or ‘unclear’ based on the information available for each domain in the included studies [113]. For selection bias, quasi-experimental trials and controlled before-and-after methodologies must be rated as ‘high risk’ for this domain, as the allocations by definition were not truly random. Completeness of descriptions of blinding of participants and personnel determined whether the study was likely to be influenced by performance bias. In terms of detection bias, the decision was taken based on the effective procedures utilised to blind the outcome assessors from knowing which procedure was received (intervention or control). The effects of the outcome assessment being blinded or not, and of how effectively it was blinded, may vary between outcomes. This is because study outcomes may be assessed subjectively or objectively by research personnel or the participants themselves; hence the need to assess each outcome. In the case of attrition bias, reasons for high risk of bias include a large number of missing data or no intention to treat analysis. For reporting bias, a decision was made based on whether selective outcomes were reported. The risk of bias for reporting bias is dependent on the availability of a study protocol. Without a protocol, a study is at unclear risk of bias even if all expected outcomes are identified and reported. Other biases were judged based on the presence of any other key concerns that were not covered by other domains in the tool and could contribute to the study’s bias.
All included studies were assessed independently for potential risk of bias by the two reviewers (HS and SNR). If there was a discrepancy in the results, the studies were reviewed again, and a decision was reached. In cases where a consensus could not be reached, discussions were arranged with a supervisor (HP or SSG) to reach an agreement. I then generated risk of bias summary graphs and figures using Review Manager 5.3 [128].

**Descriptions of intervention**

In addition to assessing the risk of bias for each paper, I assessed the quality of the descriptions of interventions of the included studies using the Template for Intervention Description and Replication (TIDieR) checklist [129]. The completeness of intervention descriptions in published studies is critical in order for other researchers or healthcare professionals to repeat the procedures accurately [129]. The TIDieR checklist contains the following 12 items to assess the reproducibility of the intervention based on the description: brief name, why, what (materials), what (procedure), who provided, how, where, when and how much, tailoring, modifications, how well (planned), how well (actual).

5.3.7 **Data synthesis and analysis**

I conducted two analyses to meet the two objectives of my systematic review.

**Assessing the effectiveness of interventions**

First, I considered the effectiveness of asthma self-management interventions which addressed health literacy needs compared with the control group. From my scoping work, I expected that the studies contained within this review would vary considerably in terms of design, target populations, outcomes measured and duration of follow-up. This heterogeneity precluded meta-analysis. Therefore, I planned to conduct a narrative synthesis of the data. Based on the number of studies identified and the reported outcomes, I considered illustrating findings with a Harvest plot [130].
Choice of behaviour change framework

Second, I described and characterised the included interventions using a behaviour change framework. Theories of behaviour change are diverse, ranging from how people become motivated to change to how this motivation is translated into actual behaviour change and how the newly changed behaviour can be sustained. Thus, when looking for a suitable behaviour change framework to guide my analysis, I considered frameworks that covered motivation and enablers for change to occur and be sustained. I also looked for a behaviour change framework that would be suitable for use throughout all the projects of this PhD for consistency and comparability. For these purposes, I considered the Theory of Planned Behaviour (TPB), Social Cognitive Theory (SCT) and the Behaviour Change Wheel (BCW).

I reviewed the TPB developed by Ajzen in 1985 [131]. This theory explores the relationship between behaviour and beliefs, attitudes and intentions [132]. A central factor in the TPB is the individual's intention to perform a given behaviour [131]. Intentions are assumed to capture the motivational factors that influence behaviour; they are indications of how hard people are willing to try and the amount of effort they are planning to exert in order to perform the behaviour [131]. The stronger the intention to engage in a behaviour, the more likely it will occur. A behaviour intention can only occur if the behaviour is under volitional control [131]. Although some framework behaviours may meet this requirement, the performance of such behaviour will also depend to some degree on non-motivational factors, such as availability of requisite opportunities, and resources, such as time and cooperation of others [131]. The framework, however, provides limited information about how to change behavioural beliefs [133]. It is commonly used to measure the process by which interventions influence behaviour rather than to develop interventions [134,135], limiting its usefulness for my study.

I considered the SCT proposed by Bandura [132]. It describes a dynamic, ongoing process in which personal factors, environmental factors and human behaviour exert influence upon each other [132]. According to SCT, three main...
factors affect the likelihood that a person will change a health behaviour: self-efficacy, goals and outcome expectancies. The framework emphasises self-efficacy, which galvanises behaviour change as well as other behavioural determinants such as intention and expected outcomes. For example, if individuals have a sense of self-efficacy, they can change behaviour despite obstacles. Similarly, as an individual adopts new behaviours, this causes changes in both the environment and the person [132]. This theory has been used successfully in the development of self-management interventions [136]. However, tenets of self-efficacy include enactive mastery experiences (e.g., a personal self-management attempt), vicarious experiences (e.g., modelling the self-management experiences of another), verbal persuasion (e.g., a close friend expressing faith in one’s abilities) and physiological and affective states (e.g., bodily experience of exacerbations) [132]. As a result, SCT-based interventions must target one or more of these sources to influence self-efficacy. These characteristics can be difficult to fulfil in order to develop an intervention, and information in assessing interventions covering these tenets may be lacking, which limits its usefulness for this PhD.

Finally, I reviewed the BCW (Figure 8) and decided to use this. The BCW framework offers an organised means to describe and characterise the techniques used in the interventions in this review [137,138] and has broader use in other phases of this study. It was developed to meet three criteria (comprehensiveness, coherence and an overarching model of behaviour) not met by 19 existing frameworks of behaviour change, as identified by a systematic literature review [137,138]. Thus, this framework is suitable to assist in designing and evaluating interventions and policies concerning behaviour change. The BCW has three layers. At its core are the COM-B components (Capability, Opportunity and Motivation). The interactions between these components shape Behaviour [137].
Chapter 5: Systematic review

Figure 8 The Behaviour Change Wheel (BCW).

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- Capability is defined as an individual's psychological and physical capacity to engage in the behaviour. It consists of having the expected knowledge and competence.

- Opportunity comprises aspects of the physical and social environment beyond the individual that incite the behaviour or make it possible.

- Motivation is construed as processes that lead towards both reflective and automatic mechanisms that trigger or suppress behaviour.

The second layer of the BCW identifies the nine functions of interventions formulated to change behaviour. The functions are education, persuasion, incentivisation, coercion, training, enablement, modelling, environmental restructuring and restrictions. The third layer of the BCW describes seven types of policies (e.g., legislation and fiscal measures) that could address these intervention functions [137]. It is suggested that explicit intervention functions are expected to affect change in the particular target behaviour. This
framework underpins a matrix developed through a consensus exercise among behaviour change experts [137]. The matrix enabled the mapping of intervention functions required to impact the three core components (capability, opportunity and motivation) governing behaviour change [137]. This framework can be used to assess and design an intervention which will have broader applicability in my study.

**Identifying components in the included studies**

Using this matrix, I then plotted the components of interventions in this review onto the matrix. Two reviewers (HS and KMcc) completed the mapping process independently. We first identified the core components of behaviour that were targeted and the intervention functions used in each included study. Then, through a consensus approach (Appendix 11), we plotted our findings within the matrix.

**5.4 Results**

I illustrated the selection process in a PRISMA diagram (Figure 9). From 3,359 papers, I selected six papers describing five controlled experimental trials, including four RCTs [115,117,139,140] and a controlled trial [116] (the sixth paper described the development of the intervention of one of the trials [139,141]). A total of 731 participants were involved in the intervention groups, while 561 participated in the studies’ control groups [115-117,139,140].

**5.4.1 Characteristics of included studies**

The studies included in this review were conducted between 2011 and 2017; four studies were conducted in high-income countries [115,117,139,140] (three in the United States and one in Canada) and one in Turkey (a middle-income country) [116]. Table 10 summarises the population characteristics.
Participants’ characteristics: The three US studies involved majority and minority populations [115,117,140]. Most of the population in the study by Macy et al. (2011) were White Americans. Yin et al. (2017) included primarily Latin Americans (Hispanics), while Apter et al. (2011) recruited mainly African Americans. In Canada, the trial performed by Poureslami et al. (2012) included participants from minority Chinese and Punjabi ethnic groups [139]. The study conducted in Turkey by Ozyigit et al. (2014) did not specify the population’s ethnicity [116]. Participants’ asthma status was described as uncontrolled [115,116]; mild intermittent, persistent or moderate-to-severe asthma [140]; and mild asthma [117]. One study did not report the participants’ level of asthma control [139].
<table>
<thead>
<tr>
<th>STUDY (YEAR); COUNTRY</th>
<th>POPULATION CHARACTERISTICS</th>
<th>Aim</th>
<th>Ethnicity (main); participants; sample age; sample size (Intervention/Control)</th>
<th>Socioeconomic status; limited health literacy level; health literacy tool used</th>
<th>Baseline asthma control</th>
<th>Geographical area; setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Apter et al. (2011); USA [115].</td>
<td></td>
<td></td>
<td>Investigate the use of a problem-solving (PS) approach to improve medication adherence in patients with moderate or severe asthma.</td>
<td>Mixed majority and minority population (African American); patients; over 18 years; 333 (165/168)</td>
<td>Low-income; 31.2 + 7.3(^a); sTOFHLA Mean ACQ score (^b): 1.7 ± 1.1</td>
<td>Urban; primary care and asthma specialty practices</td>
</tr>
<tr>
<td>Macy et al. (2011); USA [117].</td>
<td></td>
<td></td>
<td>Compare the change in asthma knowledge among parents with low or adequate health literacy after delivery of intervention during child’s asthma-related emergency department (ED) visit.</td>
<td>Mixed majority and minority population (Caucasian); parents; over 19 years; 129 (62/67)</td>
<td>Low-income; 31% (27/86); REALM Pulmonary Index Score (^c): 1</td>
<td>Urban; secondary care (ED)</td>
</tr>
<tr>
<td>Ozyigit et al. (2014); Turkey [116].</td>
<td></td>
<td></td>
<td>Assess the effectiveness of a pictorial asthma action plan on asthma control, health-related quality of life (HRQoL) and asthma morbidity in a population of illiterate women with asthma.</td>
<td>Majority ethnic group; patients; 18–55 years; 34 (18/16)</td>
<td>Socioeconomicall y underdeveloped; –; –</td>
<td>—; secondary (primary care hospital outpatient clinic)</td>
</tr>
</tbody>
</table>

Table 10 Overview of population characteristics of included studies.
<table>
<thead>
<tr>
<th>STUDY (YEAR); COUNTRY</th>
<th>POPULATION CHARACTERISTICS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Aim</strong></td>
<td><strong>Ethnicity (main);</strong></td>
</tr>
<tr>
<td>Poureslami et al. (2012); Canada [139].</td>
<td>participants; sample age; sample size (Intervention/Control)</td>
</tr>
<tr>
<td><strong>Aim</strong></td>
<td><strong>Socioeconomic status; limited health literacy level; health literacy tool used</strong></td>
</tr>
<tr>
<td>Poureslami et al. (2012); Canada [139].</td>
<td></td>
</tr>
<tr>
<td>Poureslami et al. (2012); Canada [139].</td>
<td></td>
</tr>
<tr>
<td><strong>Aim</strong></td>
<td><strong>Geographical area; setting</strong></td>
</tr>
<tr>
<td>Yin et al. (2017); USA [140].</td>
<td>Explore the effectiveness of different formats of culturally relevant information and its impact on asthma patients’ self-management within the Punjabi, Mandarin and Cantonese communities.</td>
</tr>
<tr>
<td>Yin et al. (2017); USA [140].</td>
<td></td>
</tr>
<tr>
<td>Yin et al. (2017); USA [140].</td>
<td>Low-income; 69.9% (151/217); NVS</td>
</tr>
</tbody>
</table>

**NOTES:**

- Short Test of Functional Health Literacy in Adults (score range, 0–36, with a score of 23 or greater adequate);
- ACQ score less than 0.75 = well-controlled;
- Pulmonary Index Score assesses asthma severity (IQR 0–4);
- ACT score more than 19 indicates well-controlled asthma.

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**Study setting:** Two studies were conducted in primary care settings [115,116]. Three studies were conducted in secondary or tertiary care settings (specialist paediatric [140] or ED [117], university-based pulmonary medicine clinic [139]).

**Geographical area and socioeconomic status:** Four studies were described as set in an urban location [115,117,139,140]; three described their population as of low socioeconomic status [115,117,140], while the fourth stated that less than a third were in the ‘working-class group’ [139]. The non-urban study identified the population as living in the country’s most socioeconomically under-developed area [116].

**Health literacy status of the population:** Only three studies tested the participants’ level of health literacy. A study which used the validated NVS estimated that 70% of the study population had limited health literacy levels [140]. Two other studies assessed the health literacy level of the study population using the Short Test of Functional Health Literacy in Adults (sTOFHLA; affirming that the mean reading comprehension score was ‘adequate level’ [115]) or the Rapid Estimate of Adult Literacy in Medicine (REALM; describing that ‘two-thirds of the study population had an adequate level of health literacy’) [117]. Although, in these two studies, less than 50% of the study population had limited health literacy, based on their screening [115,117], I included these studies because the intervention approach met the criteria of an asthma self-management intervention explicitly aimed to improve health literacy using techniques described by Sheridan et al. [87] (Table 7). Two other studies included ‘immigrants’ [139] or ‘illiterates’ [116] as their study population, which accounts for 9.2% of the total participants of all the included interventions.

**Intervention characteristics:** Table 11 summarises the interventions. All studies featured one intervention and one control group [115-117,140] except one study, which had three intervention groups (physician-led educational video, patient-generated community video, both videos) [139].
Table 11 Overview of the interventions’ characteristics.

<table>
<thead>
<tr>
<th>STUDY (YEAR); COUNTRY</th>
<th>INTERVENTION CHARACTERISTICS</th>
<th>Control/other group description</th>
<th>Procedure; language used</th>
<th>Mode of delivery; length of intervention</th>
<th>Tailored to health literacy level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Apter et al. (2011); USA [115].</td>
<td>Problem solving (PS) comprised four 30-minute sessions. The individualized intervention involved four interactive steps, usually one per research session. The first step involved breaking problems into small achievable pieces. The second step was brainstorming for alternative solutions. The third step was choosing the best solution by weighing the desirable and undesirable consequences of each candidate solution. Between the third and fourth meetings, the solution was tried. Then, for the fourth step, the chosen solution was evaluated and revised. As part of this intervention, downloaded data from monitored inhaled corticosteroids (ICSs) were shared with the participant in a non-judgmental fashion at each visit. At these sessions, subjects followed the same PS steps for addressing an additional problem of their choosing. Duration: 30 minutes.</td>
<td>Asthma Education (AE), like PS, comprised four 30-minute sessions, each about an AE topic unrelated to self-management, adherence or ICS therapy. The topics covered, one at each session, were the following: (1) the proper technique for using an albuterol rescue metered-dose inhaler and a dry powder inhaler or spacer, depending on the patient’s medications (2) the use of peak flow meters (3) common asthma triggers (4) the pathophysiology of asthma. These sessions did not involve discussion of PS or adherence, only didactic presentation of health information.</td>
<td>Questionnaires on sociodemographic, present and past asthma status and comorbidities were completed. Spirometry results were obtained. Participants estimated their adherence over the last three months with the Inhaler Adherence Scale. An electronic monitor was attached to participants’ ICS-containing inhalers. Participants were informed that the monitor recorded the time and date of inhaler actuation and that data would be downloaded at each of eight study visits. Two weeks later (visit 2), subjects were randomised to a computer-generated algorithm in a 1:1 ratio to either PS or AE. Subjects met with research coordinators monthly for four sessions (visits 2–5) of either PS or AE, spirometry, and downloading monitor data. The need for urgent medical care since the last visit was explored. Subjects then continued to meet monthly with research coordinators for three additional months (visits 6–8) to download monitor data, but no PS or AE occurred at visits 6 to 8. Language: English and Spanish.</td>
<td>Face-to-face. Length: 6 months.</td>
<td>No tailoring was made, but PS is a component of health literacy defined by Sheridan et al. [87].</td>
</tr>
<tr>
<td>STUDY (YEAR); COUNTRY</td>
<td>INTERVENTION CHARACTERISTICS</td>
<td>Control/other group description</td>
<td>Procedure; language used</td>
<td>Mode of delivery; length of intervention</td>
<td>Tailored to health literacy level</td>
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<tr>
<td>Macy et al. (2011); USA [117].</td>
<td>The intervention used video-based asthma educational materials. In the intervention group, participants (carers of children with asthma) viewed a video entitled 'Roxy to the Rescue' before being discharged from the emergency department (ED). The video was developed by the New England Research Institute, which targets urban families with asthmatic children. This animated video consists of educational messages, including the following: 1) basic facts about asthma 2) roles of medications 3) patient’s skills. Duration: 20 minutes.</td>
<td>The active-control group received written educational materials to review in the ED or home. The written materials were developed by the Michigan Department of Community Health and are standard educational materials used across Michigan.</td>
<td>Subjects were recruited when presenting to ED to evaluate respiratory symptoms in their 2- to 14-year-old child who had physician-diagnosed asthma or a history of wheeze. Eligible parents completed a verbally administered baseline survey (child asthma history, current symptoms, healthcare utilisation, demographic characteristics, parental baseline knowledge and sense of control). After baseline data collection, they were randomised to the intervention and control groups. The participants were contacted by telephone 4–6 weeks after study enrolment. The research assistant was blinded to the type of intervention received by participants and to their measured knowledge and sense of control during this phone call. Participants also reported on the frequency of the child’s asthma symptoms and healthcare utilisation. Language: Not specified.</td>
<td>The intervention was delivered using video, and follow-up was done using a telephone call. Length: 5 weeks.</td>
<td>Although the intervention was not tailored to health literacy level, an alternative method of delivering educational materials was used (video-based), as described by Sheridan et al. [87].</td>
</tr>
<tr>
<td>STUDY (YEAR); COUNTRY</td>
<td>INTERVENTION CHARACTERISTICS</td>
<td>Control/other group description</td>
<td>Procedure; language used</td>
<td>Mode of delivery; length of intervention</td>
<td>Tailored to health literacy level</td>
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<tr>
<td>Ozyigit et al. (2014); Turkey [116].</td>
<td>The intervention used a pictorial asthma action plan (PAAP) previously used among asthma patients with a low level of education. The PAAP has three columns. The first column indicates that, when a symptom appears, the patients should use their rescue medication in addition to their standard treatment. The second column indicates that when the frequency of use of the rescue medication increases, the patient should take methylprednisolone (16 mg tablet 1 or 2 a day) for five days and use a proton pump inhibitor prescribed for gastric protection after informing their physician. The third column indicates that in the presence of symptoms after methylprednisolone treatment, the patient should call their physician and present to an ED. PAAP was given on top of education, which was also given to the control group. Duration: not specified.</td>
<td>The education material was prepared on slides which included illustrations, and the content involved basic mechanism, symptoms of asthma, roles of each medication (symptomatic and preventive medication), administration techniques for any device, signs for exacerbation and environmental control.</td>
<td>Patients were alternately assigned to either the intervention or the control group based on their admittance order to the department. Both groups were given an interactive asthma education lesson presented by the same respiratory physician on the same planned day. Baseline assessment was conducted, including ACT (asthma control test) and SGRQ (St George Respiratory Questionnaire). The tests were applied to every participant before the education head-to-head, and at the first, second and sixth-month follow-ups by telephone, interviews were done by the same assessor. Language: Not specified but potentially in the local language.</td>
<td>Face-to-face or paper-based asthma action plan (AAP). Length: 6 months.</td>
<td>Tailored for the illiterate woman (using images to improve the ability to understand).</td>
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<tr>
<td>STUDY (YEAR); COUNTRY</td>
<td>INTERVENTION CHARACTERISTICS</td>
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<td></td>
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<td>-----------------------</td>
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<tr>
<td>Poureslami et al. (2012); Canada [139].</td>
<td>The intervention involved the development of educational videos using a community participatory approach. Two videos (knowledge and community) were culturally and linguistically appropriate, including people’s views and perceptions about health. In the knowledge video, scientific information was given, such as asthma symptoms, how to avoid asthma environmental-related and behavioural-related triggers and how to manage an asthma attack. In the community video, community opinions and narratives were used covering the community members’ cultural beliefs and practices about asthma and its management using social interactive communication styles. Finally, an educated elder addressed potential misconceptions about asthma, provided correct information on managing asthma and encouraged early intervention. Duration: not specified.</td>
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<tr>
<td>Control/other group description</td>
<td>A pamphlet was reverse-engineered from the knowledge video to use the same content but a different presentation format.</td>
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<tr>
<td>Procedure; language used</td>
<td>Eligible subjects were randomly assigned to three experimental groups and viewed Grp 1: a physician-led knowledge video Grp 2: a patient-generated community video Grp 3: both videos One comparison group read Grp 4: an educational pamphlet Immediately after reviewing the educational materials, the participants were asked to study a questionnaire, include questions about knowledge of asthma symptoms, knowledge of asthma triggers and triggers that could make asthma worse, understanding physician instruction on medication use and proper use of an inhaler. The intervention was done at the one-month point after the pre-test assessment. Follow-up lasted for nine months, with assessments being done pre-intervention and at the three-month point. At a six months post-follow-up post-test assessment, patients were assessed for their self-management practices. Language: Punjabi and Mandarin.</td>
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</tr>
<tr>
<td>Mode of delivery; length of intervention</td>
<td>Video-based delivery and face-to-face assessment. Length: 9 months.</td>
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<tr>
<td>Tailored to health literacy level</td>
<td>The educational materials were developed to align with the health literacy definition by Nutbeam et al. [77] of critical health literacy, where advanced cognitive and social skills were needed to ensure critical analysis of the situation.</td>
<td></td>
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<tr>
<td>STUDY (YEAR); COUNTRY</td>
<td>INTERVENTION CHARACTERISTICS</td>
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<tr>
<td></td>
<td>Intervention description and duration of delivery</td>
<td>Control/other group description</td>
<td>Procedure; language used</td>
<td>Mode of delivery; length of intervention</td>
<td>Tailored to health literacy level</td>
</tr>
<tr>
<td>Yin et al. (2017); USA [140].</td>
<td>The intervention was a low-literacy, plain language, pictogram- and photograph-based AAP. A hypothetical AAP was created involving commonly prescribed medications. The tool focused on three areas of chronic asthma management recognised as confusing for parents: 1) medications to give every day, even when the child is sick 2) the need for a spacer to maximise medication delivery to lungs 3) appropriate emergency response. The intervention emphasised these key messages by incorporating specific low-literacy techniques such as plain language, pictorial illustrations, photographs and optimisation of design elements. Duration: not specified.</td>
<td>Parents in the control group received a standard action plan developed by the American Academy of Allergy Asthma &amp; Immunology. The medication regimen for the hypothetical child, Jason, was typed in. In each zone, medications information was filled in by the provider within a table format. All information was presented in text format.</td>
<td>Parents were randomly assigned to the intervention and control groups. Randomisation was done using sealed envelopes in a block of 50 in each. The lead project coordinator was responsible for the randomisation procedure, but research assistants were blinded to randomisation. Baseline assessments of sociodemographic and asthma-related characteristics were collected before assessment using a written AAP. Action plans were presented to parents concealed within a portfolio, and they were instructed not to reveal the action plan to the interviewer. Participants were assessed on their knowledge of 1) green zone knowledge 2) red zone knowledge. Parents were asked to refer to the action plans they were given to answer questions. They were allowed to take as much time as needed to respond. Language: English and Spanish</td>
<td>Face-to-face. Length: Nil.</td>
<td>The level of health literacy among parents was not measured quantitatively. However, the intervention was tailored to the low-literacy status described by Sheridan et al. [87].</td>
</tr>
</tbody>
</table>

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All interventions included education delivered through diverse methods: one utilised a face-to-face, individualised, problem-solving approach [115], two used video-based education [117,139], and two used education with pictorial asthma action plans [116,140], although only one of these explicitly tailored its action plan to low-literacy levels [140]. Three interventions were delivered by research assistants [115,116,140] and one by a respiratory physician [116]. Four studies specified the language used to deliver the intervention: English or Spanish [115,140], ‘native language’ [116] and Punjabi or Mandarin [139]. Two studies detailed the intervention’s delivery duration: 20-minute video [117] or four 30-minute problem-solving sessions [115]. The period of follow-up varied from five weeks to a year [115-117,139]. One study evaluated the immediate understanding of a pictorial asthma action plan [140] rather than longer-term outcomes.

5.4.2 Quality assessment of the included studies

Only one study was at an overall low risk of bias, including the domains of selection bias, performance bias, detection bias, attrition bias and reporting bias [140] (Figure 10). The high risk of bias in the other four studies was typically due to high risk of bias in selection bias, performance bias and other bias [115-117,139]. Other biases included no specified sample size [115,116] and the use of non-validated tools to measure outcomes [139].

*Figure 10 Risk of bias summary: judgement about each risk of bias item for each included study. Adapted from the Journal of Global Health.*

<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td><strong>Selection bias:</strong> Random sequence generation</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>?</td>
</tr>
<tr>
<td><strong>Selection bias:</strong> Allocation concealment</td>
<td>✔️</td>
<td>?</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td><strong>Performance bias:</strong> Blinding of participants and personnel</td>
<td>✔️</td>
<td>?</td>
<td>✔️</td>
<td>?</td>
<td>✔️</td>
</tr>
</tbody>
</table>
**Detection bias**: Blinding of outcome assessment  
- Low risk  
- High risk  
- Unclear

**Attrition bias**: Incomplete outcome data  
- Low risk  
- High risk  
- Unclear

**Reporting bias**: Selective reporting  
- Low risk  
- High risk  
- Unclear

**Other bias**  
- Low risk  
- High risk  
- Unclear

**Overall bias across all domains**  
- Low risk  
- High risk  
- Unclear

Notes:  
- Low risk  
- High risk  
- Unclear

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I described the risk of bias assessment for every domain of the tool: selection bias (random sequence generation, allocation concealment), performance bias, detection bias, attrition bias, reporting bias and other biases. For random sequence generation, one study scored low risk [115] for describing the randomisation process. In this study, for example, randomisation sequence was generated using a computer-generated algorithm in a 1-to-1 ratio to either control or intervention group [115]. One study did not provide sufficient details of the random sequence generation [140], and one of the high risk studies, for example, used admittance order to the clinic to allocate participants to control and intervention groups [116]. For allocation concealment, three studies were rated high risk, two of them due to the nature of the intervention [115,139]; one study used non-randomised techniques for allocation, and thus, allocation sequence concealment may not have been ensured from those enrolling patients into the study [116]. For performance and detection bias, blinding was not possible for an intervention involving problem-solving support; thus, the study was scored high risk [115]. The blinding of personnel and participants were not clearly described in the other RCT [139].

Most studies provided information on missing outcome data or reported on drop-outs [115,117,140]. For selective reporting, one study did not provide complete outcomes, and several outcomes were reported as in-text descriptions [117]. Other biases included no specified sample size [115,116] and non-validated tools to measure outcomes [139]. The risk of bias assessment was undertaken by the two reviewers (HS and SNR); however, in
some instances, a consensus was reached after discussion with a third reviewer (HP or SSG; Appendix 12).

5.4.3 Quality of description and replication
Each of the studies detailed the justification for its intervention’s core components, but none were guided explicitly by a theoretical framework. Three studies lacked descriptions of how the intervention was delivered [117,139,140]. For example, one report was equivocal about whether the video-based intervention was administered individually or in groups [117]. Details of the descriptions of the included interventions are provided in Appendix 13 of the TIDieR checklist. Key features of the checklist are reproduced in tables of characteristics (Table 10 and Table 11).

5.4.4 Effectiveness of interventions on primary and secondary outcomes
Table 12 summarises the clinical and process outcomes of the included studies.

Primary health outcomes: asthma control and unscheduled care

- **Impact on asthma control**
The study at low risk of bias did not report any of the primary clinical outcomes [140]. Two studies at high risk of bias assessed asthma control using validated questionnaires (Table 11 and Table 12) [115,116]. Neither influenced asthma control.

- **Impact on unscheduled care**
Three studies at high risk of bias measured their interventions’ impacts on unscheduled care [115-117]. One study reported reduced emergency visits in the intervention group compared to the control [116]. One study only reported within-group changes, stating no between-group difference, but no statistical comparison was provided [115].
Primary implementation outcome: uptake or completion of the intervention

None of the five studies assessed implementation results, such as uptake or completion of the intervention.

Secondary outcomes:

• Impact on knowledge
  The study at low risk of bias reported a positive outcome for knowledge [140], while the other studies reported no effect [117,139] (Table 12).

• Impact on correct inhaler use
  A study at high risk of bias reported education components which included education to impart skills on inhaler use. However, the data presented were unclear, and it was not possible to clarify whether this factor had an impact or not [139].

• Impact on other practical self-management measures
  Other measures reported by the studies included in this review were as follows: perceived ease of action plan use, understanding of low-literacy asthma action plan (low risk of bias) [140], perceived sense of asthma control [117], understanding of physicians’ instruction [139] and adherence [115] (high risk of bias) (Table 12).
**Table 12 Summary of the impact of clinical and process outcomes categorised by health literacy status of the population.**

<table>
<thead>
<tr>
<th>Citation; design; follow-up (FU); n; ethnicity; age; health literacy (HL) status; asthma control; risk of bias</th>
<th>Intervention summary</th>
<th>Reported outcomes</th>
<th>Interpretation of effectiveness</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health literacy status of the population:</strong> All populations with limited health literacy (assumption based on quantitative and qualitative evidence in the literature)</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
| **Poureslami 2012** [139] Canada; randomised control study; FU: 3 months; one centre, 85 adults; minority population (Chinese and Punjabi); at least 21 years; HL status: –; baseline asthma control: –; overall risk of bias: High risk | Participants watched videos on asthma knowledge and/or the community’s cultural views on asthma. Study groups: IK: Knowledge video IC: Community video IK+C: Both videos C: pictorial leaflet | **Asthma control**

* Inhaler technique

*Indicates the trial’s primary outcome (if stated).**

<table>
<thead>
<tr>
<th></th>
<th>Reported outcomes</th>
<th>Interpretation of effectiveness</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Unscheduled care</strong></td>
<td>No relevant outcome</td>
</tr>
<tr>
<td></td>
<td>No relevant outcome</td>
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</tr>
<tr>
<td></td>
<td><strong>Knowledge:</strong></td>
<td>No between-group comparison. ‘Proper use of inhalers improved significantly among all experimental groups over time, p &lt; 0.001.’ No comparison between intervention groups, and no control-group comparison. There was a significant difference in mean scores in the improvement of knowledge in asthma symptoms, triggers and the understanding of physician instructions on medication use between intervention groups and control, p &lt; 0.05’</td>
</tr>
</tbody>
</table>
| | *Understanding physician instructions on medication use:* within-group comparison of inhaler technique score at baseline and 3 months: mean (SD) MD (95% CI)

<table>
<thead>
<tr>
<th>Study group</th>
<th>Baseline</th>
<th>3 months</th>
<th>Mean difference, MD (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>IK</td>
<td>B 4.0 (2.1)</td>
<td>3m 5.9 (2.0)</td>
<td>2.71 (1.35 to 4.06)</td>
</tr>
<tr>
<td>IC</td>
<td>B 4.5 (2.0)</td>
<td>3m 6.8 (2.0)</td>
<td>1.95 (0.99 to 2.91)</td>
</tr>
<tr>
<td>IK+C</td>
<td>B 3.9 (2.1)</td>
<td>3m 6.8 (1.6)</td>
<td>1.53 (0.66 to 2.40)</td>
</tr>
<tr>
<td>C</td>
<td>B 4.8 (2.3)</td>
<td>3m 6.6 (1.4)</td>
<td>1.05 (-0.10 to 2.20)</td>
</tr>
<tr>
<td><strong>Knowledge:</strong></td>
<td></td>
<td></td>
<td>Insufficient details to gauge effectiveness.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Study group</th>
<th>Baseline</th>
<th>3 months</th>
<th>Mean difference, MD (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>IK</td>
<td>B 0.8 (0.6)</td>
<td>3m 1.4 (0.8)</td>
<td>0.53 (0.12 to 0.94)</td>
</tr>
<tr>
<td>IC</td>
<td>B 1.2 (0.9)</td>
<td>3m 1.7 (0.9)</td>
<td>0.38 (-0.06 to 0.82)</td>
</tr>
<tr>
<td>IK+C</td>
<td>B 1.7 (0.8)</td>
<td>3m 1.8 (0.6)</td>
<td>0.24 (-0.19 to 0.66)</td>
</tr>
<tr>
<td>C</td>
<td>B 1.6 (1.1)</td>
<td>3m 1.7 (0.8)</td>
<td>0.35 (-0.22 to 0.92)</td>
</tr>
</tbody>
</table>

Insufficient details to gauge effectiveness. |
<table>
<thead>
<tr>
<th><strong>Ozyigit 2017 [116]</strong></th>
<th>Participants received pictorial asthma action plans (PAAPs) and education materials. The PAAP was previously used among people with low levels of education and asthma.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Turkey:</strong> controlled study; FU: 6 months; one centre, 34 female adults; –; 18–55 years; HL status: –; baseline asthma control: Uncontrolled; overall risk of bias: High risk</td>
<td>Study groups I: PAAP + educational materials C: educational materials</td>
</tr>
<tr>
<td><strong>Asthma control</strong></td>
<td>Between-group difference at 6 months in asthma control test (ACT). Mean (SD) I: 24.0 (1.0) vs C: 23.3 (1.3), p = 0.07</td>
</tr>
<tr>
<td><strong>Health-related quality of life (QoL)</strong></td>
<td>Between-group difference at 6 months in St George Respiratory Questionnaire, SGRQ. Mean (SD) I: 53.7 (7.5) vs C: 50.3 (7.8), p = 0.21</td>
</tr>
<tr>
<td>*<strong>Unscheduled care</strong></td>
<td>Between-group difference in the number of visits to the emergency department (ED) over the 6-month study period. Mean (SD) I: 0.9 (1.2) vs C: 1.8 (2.4), p = 0.001</td>
</tr>
</tbody>
</table>
| | There was no significant difference between intervention and control for asthma control and QoL.  
**Consistently shown as no effect.** |
| | A significant difference was seen between the control and intervention groups for the number of emergency visits during the study period.  
**Consistently shown as positive effect.** |

| **Health literacy status of the population:** Majority limited health literacy, n (%) |

<table>
<thead>
<tr>
<th><strong>Yin 2017 [140]</strong></th>
<th>Participants (carers of a child with asthma) received low-literacy, plain language, pictogram- and photograph-based asthma action plans (AAPs). Parents were asked what they knew about medication used in managing asthma control</th>
</tr>
</thead>
</table>
| **US:** randomised control study; FU: post intervention; paediatric OPD carers of 217 children; | Asthma control  
**No relevant outcome** |
|  | **Unscheduled care**  
**No relevant outcome** |
|  | **Perceived ease of use**  
**Perceived ease of use (PAAP):** Between-group comparison of proportion expressing trouble reading the allocated PAAP n (%) I: 93 (85%) vs C:93 (88%), p = 0.7  
**Illustrated as consistently no effect**  
**No significant between-group difference in proportion expressing trouble reading the allocated PAAP, though when shown both PAAPs, 79% considered the low-literacy PAAP easier to understand.** |
majority Hispanic; mean age 35.5 (8.3) years; proportion with limited health literacy I: 74% vs C: 65%; baseline asthma control: mild to moderate/severe; overall risk of bias: Low risk

<table>
<thead>
<tr>
<th>Knowledge</th>
<th>Green/yellow zone knowledge</th>
</tr>
</thead>
<tbody>
<tr>
<td>Groups</td>
<td>pictorial AAP C: standard AAP</td>
</tr>
</tbody>
</table>

I: 63 (63.0) vs C: 75 (77.3), p = 0.03

Between-group comparison of the proportion of carers making errors in the knowledge of which medications to give, n (%)

I: 14 (14.0) vs C: 48 (51.1), p < 0.001

Red zone knowledge

Between-group comparison of the proportion of carers making errors in the knowledge of appropriate emergency response, n (%)

I: 47 (43.1) vs C: 52 (48.1), p = 0.5

There were significant between-group differences in the knowledge of which maintenance medications to give and knowledge of spacer use, but not in the knowledge of appropriate emergency response. Overall, has shown a positive effect, but not all outcomes are consistent.
Participants received a four-step, problem-solving intervention in the aspect of asthma and its management. The intervention allows critical evaluations of needs and concerns about asthma and its management and educates participants on how to overcome these problems.

Groups
I: problem-solving sessions (PS) + asthma education (AE)
C: asthma education (AE)

**Asthma control**

*Asthma control based on asthma control questionnaire (ACQ) score:* Within-group comparison from baseline, 3 months and 6 months: mean (SD)
I: B 1.7 (1.1) vs 3m 1.6 (1.3) vs 6m 1.5 (1.2)
C: B 1.7 (1.1) vs 3m 1.5 (1.1) vs 6m 1.3 (1.1)

*QoL based on asthma QoL score:* Within-group comparison from baseline, 3 months and 6 months: mean (SD)
I: B 4.0 (1.4) vs 3m 4.7 (1.4) vs 6m 4.7 (1.3)
C: B 4.1 (1.4) vs 3m 4.8 (1.4) vs 6m 4.8 (1.4)

*Forced expiratory volume, FEV1 % predicted:* Within-group comparison from baseline, 3 months and 6 months: mean (SD)
I: B 4.0 (1.4) vs 3m 4.7 (1.4) vs 6m 4.7 (1.3)
C: B 4.1 (1.4) vs 3m 4.8 (1.4) vs 6m 4.8 (1.4)

No between-group comparison for QoL and FEV1 predicted.

‘Asthma control improved significantly (p = 0.002) for both groups, but there was no significant statistical or clinical difference between groups.’

‘FEV1 per cent predicted and quality of life improved from baseline: (p = 0.01) and (p < 0.0001).’

There was no effect on asthma control. Insufficient details to gauge effectiveness for QoL and FEV1 predicted.
| overall risk of bias: High risk | **Unscheduled care**  
*Percentages of reports of an ED visit due to asthma since the last visit:*  
Within-group comparison from baseline, 3 months and 6 months, %  
I: B 4.3 vs 3m 6.2 vs 6m 7.3  
C: B 4.8 vs 3m 4.2 vs 6m 3  

*Percentages of reports of hospitalisation due to asthma since the last visit:*  
Within-group comparison from baseline, 3m and 6m, %  
I: B 1.8 vs 3m 2.8 vs 6m 1.5  
C: B 3 vs 3m 2.8 vs 6m 0.7  

No between-group comparison for proportions of ED visits and hospitalisation due to asthma.  
There was no difference between the PS and AE groups concerning ED visits for asthma (p = 0.51) and hospitalisations for asthma (p = 0.79).  
Consistently shown as no effect. |}

| Adherence  
*Inhaled corticosteroid (ICS) adherence from data-time record of downloaded data from the ICS monitors:*  
Within group comparison from baseline, 3 months and 6 months, mean (SD)  
I: B 61 (26) vs 3m 58 (28) vs 6m 55 (29)  
C: B 61 (28) vs 3m 53 (27) vs 6m 52 (28)  

No between-group comparison for ICS adherence.  
Insufficient details to gauge the effectiveness. |
| Macy 2011 [117] | Participants (carer of a child with asthma) received video-based asthma education materials after receiving care at the ED. Groups I: video-based asthma education material C: written asthma education material | Asthma control

*Unscheduled care*

Healthcare utilisation at 5-week follow-up:
Within-group comparison of a return visit to the primary care practitioners (PCP) between low and adequate health literacy carers, n (%)
I: LHL 71.4 vs AHL 57.1, p = 0.5
C: LHL 23.1 vs AHL 67.7, p = 0.009

Healthcare utilisation at 5-week follow-up:
Within-group comparison of a return visit to the ED between low and adequate health literacy carers, n (%)
I: LHL vs AHL 57.1, p = 0.5
C: LHL 23.1 vs AHL 67.7, p = 0.009

Perceived sense of asthma control

Perceived sense of asthma control at baseline and at 5-week follow-up: Both-group comparison between low and adequate health literacy carers, median (IQR)
LHL: 29 (27.3) vs AHL: 30 (28.3), p = 0.45 |

| US; randomised control study; FU: 5 weeks; one centre, carers of 86 children; majority White American; over 19 years; proportion with limited health literacy, n (%), total: 27 (31%); baseline asthma control: mild; overall risk of bias: High risk | Insufficient details to gauge the effectiveness. | No relevant outcome |

There was a significant difference between the proportion of parents with limited and adequate health literacy within the control group in terms of visits to PCP and ED visits. However, the difference between intervention and control is not mentioned.

**Insufficient details to gauge the effectiveness.**

No between-group comparison. Perceived sense of asthma control of both groups remained unchanged at follow-up.

**Insufficient details to gauge the effectiveness.**
<table>
<thead>
<tr>
<th>Knowledge</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change in asthma knowledge score at baseline: Both-group comparison between low and adequate health literacy carers, %</td>
</tr>
<tr>
<td>LHL: 33.3 vs AHL: 59.3, p = 0.025</td>
</tr>
</tbody>
</table>

| |
| No between-group comparison. 'Improvement in asthma knowledge at follow-up was detected for low-literacy parents regardless of the type of educational intervention, p < 0.001' |

Consistently shown as no effect.

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5.4.5 **Identification of intervention components in relation to behaviour change**

Figure 11 illustrates the core components of behaviour and the intervention functions used in the included studies. Reporting was sometimes limited: for example, one intervention described providing ‘patient skills’ in its education video [117]; however, the details of the components of such education and skills training was lacking.

**Use of Behaviour Change Wheel core components**

In terms of the use of the BCW core components of behaviour (COM-B), three studies (one at low risk and two at high risk of bias) only addressed ‘capability’ in their interventions [116,117,140] (Figure 11). Two studies (at high risk of bias) addressed a combination of capability and motivation [115,139] (Figure 11).

*Figure 11 The use of the core components of behaviour in COM-B framework in the included studies.*

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I used the published matrix [137] in Table 13 to plot the included studies according to the core components of behaviour change and intervention.
function (Appendix 11 describes the detail of the mapping process). This matrix links the core components that drive behaviour (COM-B) to the intervention functions [137,138], and the green boxes were identified as a consensus exercise by a group of experts [137,138] and are published as a resource for researchers. I undertook the mapping process with KMcC, and this was done independently, compared and later discussed. The results of the sequential steps of the process were as follows:

i) We initially identified the BCW core components of behaviour and the intervention functions used in each included study in a table (Appendix 11).

ii) We then compared our decisions and discussed any differences to conclude the intervention’s BCW core components and intervention functions.

iii) Working together, we then plotted our findings within the matrix (Table 13).

The studies in this review are placed in the boxes based on the targeted behaviours and the intervention functions used in each intervention. Green boxes without studies are intervention functions that were not used in the included studies, thus representing gaps that could be targeted in future interventions. The study at low risk of bias used only one intervention function (enablement) [140]. Of the studies at high risk of bias, two used three intervention functions [116,139], and two studies used two intervention functions [115,117] (Table 13).

In line with a suggestion by Michie et al. (2011) that the core components of behaviour can be linked to the interventions in more than one way [138], we plotted some items in more than one cell. As an example, the use of a pictorial action plan by Ozyigit et al. [116] is ‘education’, as it increases the capability to understand asthma self-management. A pictorial action plan is also a form of ‘enablement’, as it reduces barriers (e.g., lack of knowledge or cognitive skills) to self-management of asthma in the event of deterioration. Most of the interventions concentrated on capability components of the behaviour framework, and these interventions used functions such as education, training, persuasion and enabling interventions (action plans) to produce behaviour change.
Mapping Behaviour Change Wheel techniques to effectiveness

Limited reporting and the lack of effectiveness in the included studies meant that it was not possible to map the components of BCW to effectiveness.
Table 13 Mapping of core components of behaviour and intervention functions used in the included studies.

<table>
<thead>
<tr>
<th>Core components of behaviour, the COM-B framework</th>
<th>Intervention functions</th>
<th>Education</th>
<th>Persuasion</th>
<th>Incentivisation</th>
<th>Coercion</th>
<th>Training</th>
<th>Restriction</th>
<th>Environmental restructuring</th>
<th>Modelling</th>
<th>Enablement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Capability</td>
<td>physical</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>psychological</td>
<td>Macy et al. [117]</td>
<td>Poureslami et al. [139]</td>
<td>Ozyigit et al. [116]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Opportunity</td>
<td>physical</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>social</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Motivation</td>
<td>automatic</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>reflective</td>
<td>Apter et al. [115]</td>
<td>Poureslami et al. [139]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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**Note:** The green boxes indicate where the consensus group considered that intervention functions linked to the COM-B framework. For example, (1) physical capability can be achieved through physical skill development, which focuses on training and enabling interventions; (2) psychological capability can be achieved through education, training and enabling interventions; (3) reflective motivation can be achieved through education, persuasion, incentivisation and coercion; (4) physical and social opportunity can be achieved through intervention functions including training, restriction, environmental restructuring, modelling and enablement.
5.5 **Discussion**

5.5.1 **Summary of findings**

This review presents the synthesised data from five studies, including four RCTs, three of which were at high risk of bias. One other trial which was at high risk of bias used non-randomised controlled study designs. The only study at low risk of bias did not report health outcomes. I could not establish the overall effectiveness of any of my primary outcomes of interest due to study design limitations and the dearth of studies.

Most studies [115-117,140] included in this review did not describe any theoretical framework underpinning the intervention development. However, one conducted prior exploratory work to understand health literacy’s impact on the targeted population [139]. Education, training and enablement are the intervention functions used in these interventions, and the content and delivery methods varied, including video-based [117,139] and a pictorial action plan [140]. All the interventions used behavioural change components primarily directed at individuals’ (physical and psychosocial) capabilities; two addressed self-motivation; none targeted opportunity.

5.5.2 **Strengths and limitations of this review**

I followed Cochrane methodology to search systematically for trials of interventions addressing health literacy in the specific context of asthma self-management. All the review stages were duplicated, including selecting papers, risk of bias assessment and data extraction. My decision not to search some LMIC-focused databases may have resulted in missing some relevant studies, though my initial scoping exercise, in discussion with a medical librarian, suggested this was unlikely. I defined my outcomes with care, ensuring I looked for standardised asthma symptom control measures and risk of attacks [120]. I included trials based on an evidence-based definition of limited health literacy [36,119].

I applied the BCW, a validated framework, to define each of the intervention functions. A multidisciplinary team examined the interpretation of findings to
assure veracity. Unfortunately, less than half of the interventions in this review reported on asthma control [115,116] or unscheduled care [115-117], so that I could not assess the impact of these interventions on health outcomes. For example, there were inadequate data to showcase my findings graphically, (e.g., in a Harvest plot [118]) or using the GRADE [114] approach to assessing the quality of evidence). In some interventions, the description was inadequate. I could not, for example, be certain whether the ‘patient skills’ described as being included in educational videos in one trial [140] covered behaviour change techniques such as demonstration of behaviour and/or instruction on how to perform the task.

5.5.3 Interpretation of the findings and comparison with previous findings

The concept of health literacy

Health literacy is a complex concept, and several definitions have been advocated by researchers and organisations [36]. Every health literacy instrument varies, as the items range from screening to performance-based measures. This is because each tool is used to measure different constructs reflecting the different definitions and concepts. Other variables include mode of administration, time to complete, and how scores are calculated. Even more importantly, thresholds defining the different health literacy levels vary between these tools after adjusting for non-response bias [143]. Thus, the limitations of each tool must be considered when using different tools to define inclusion criteria for a study. In this review, I used a systematically defined definition by Sørensen et al. (2012) [36] to inform identification of potential studies.

Only one study [139] in this review developed its intervention based on a recognised definition of health literacy – that by Nutbeam et al. (2000) [37]. Poureslami et al. (2011) coordinated their asthma educational materials within the interpretation of ‘critical health literacy’, which demands adequate analytical skills to recognise, analyse and act independently on adversities in life to care for asthma [141]. In their prior qualitative work, language was a
barrier to understanding health information [144]. Therefore, the education material was presented using the participants’ spoken languages and was devised to help participants grasp asthma-related concepts from the ethnocultural perspective in the trial [139]. Four other studies [115-117,140] did not use specific health literacy definitions or a theoretical framework, although they used interventional designs which explicitly aimed to improve health literacy (e.g., pictograms) as defined by the operational definitions (Table 8).

**The use of theory in developing a complex intervention**

No study described any theoretical framework that informed their intervention’s development, implying that the authors may not have systematically considered the interrelated barriers among people who struggle with limited health literacy in order to identify factors that could overcome these barriers. Similarly, in the literature, a systematic review reported that in implementation research, less than a fifth (14%) of studies employed theory [145]. In a multidisciplinary environment of implementation research, selecting the most appropriate theory from a long list of options can be challenging [146]. Working with health psychologists or those familiar with theories is helpful. A ‘simple’ theory befitting various healthcare settings could enable wider adoption by researchers and support healthcare professionals in developing interventions.

There are several frameworks and guidance documents for the development of complex interventions. Some examples were described in section 4.2.1, including 6SQuID [107], a model that has not yet been used for development for asthma self-management or health literacy interventions but has been used successfully in intervention development for other conditions [110]. A framework or guidance is required to support intervention development, to guarantee that the programme of work has a strong rationale and that the development process is carried out in a structured manner to ensure cost and time effectiveness. Furthermore, in the absence of any such framework or guidance, it is challenging to envision how the intervention operates to bring about change [147,148]. Interpreting effectiveness is difficult if it is not clear what works and why [101,102].
The Behaviour Change Wheel: using a theoretical approach to understand the process of change and to evaluate interventions

The process of how behaviours change over time or in certain circumstances, and how behaviours influence health decision-making such as decisions about self-management, is complex. Walters et al. described in a review how interventions aimed at health literacy needs improved health literacy and showed evidence of behaviour change in patients with cardiovascular conditions (e.g., heart failure) [149]. Walters et al. highlighted two issues. Firstly, many interventions aimed at people’s health literacy needs did not involve patients in their design [149], an aspect only included in one trial in my review [141]. Secondly, Walters et al. highlighted the growth of intervention studies examining health literacy and their impact on behaviour over time but emphasised the lack of use of behaviour change principles in intervention design [149]. Interventions that are based on behaviour change principles have the potential to be more robust, effective and adaptable in the context of real life [149]. There are examples of behaviour change theories being used to explain self-management of chronic diseases [134,136,149,150]. My systematic review provides an example of application of the BCW to identify components of asthma self-management interventions that are tailored to health literacy needs concerning behaviour change [118,142]. The behaviour of interest in this review is self-management. The advantage of using the BCW approach is that it encourages intervention designers to consider the full range of options and choose the most promising through a systematic evaluation of theory and evidence [137]. My experience supports the suggestion that the BCW approach is important in evaluating the included studies for this systematic review. The BCW approach allowed me to identify all potentially relevant intervention functions and map them in a matrix. In all the asthma self-management interventions included in this review, targeted behaviour is more likely to change if the specific intervention function is employed. For example, education using video presentations enhanced inhaler techniques across the three experimental groups in one study. However, in this study, the control
group’s lack of comparison suggests it was unlikely to determine effectiveness [139].

**A multi-component approach to change behaviour**

The conclusion derived from two previous systematic reviews on self-management interventions for people with limited health literacy was that using more than one strategy in an intervention increased the probability of it being effective [86,87]. Schaffler et al. (2018) reported that interventions that employed three to four self-management skills were more effective than those using fewer [86]. Problem-solving, taking action, decision making, partnership and resource utilisation were the five self-management skills examined in that review [87]. Schaffler et al. (2018), however, only included one asthma self-management trial (other trials involved long-term conditions such as diabetes and hypertension), and the populations included were defined as people with low income rather than people with limited health literacy [86]. Sheridan et al. (2011) explicitly included studies of people with limited health literacy with varying long-term conditions in their review of 38 studies (22 RCTs, one cluster RCT, five non-RCTs and ten quasi-experiments). Overall, this review concluded that mixed-strategy interventions focusing on self-management reduced emergency visits, hospitalisations and disease severity in people with long term conditions [87].

Multiple components in terms of development and human resources incur costs in a complex intervention [151,152]. Constructing a complex intervention without a grasp of the behaviour it aims to change contributes to ineffectiveness. A much-criticised precedent is the futile UK public health campaign that concentrated on persuading responsible drinking but ignored reducing opportunity by focusing on price and availability [153]. Another point in this section is that the empty green cells of the matrix (Table 13) are gaps that a future multi-component intervention could successfully address.
5.6 Conclusion and implications for intervention development based on this systematic review

In this review, I learned the following:

- The development of intervention may require theoretical soundness, necessitating the use of a framework to inform its development.
- Based on the BCW framework, intervention functions that were not used in the included studies represented gaps that could be utilised in future interventions.
- Involving stakeholders, particularly end-users such as patients, at the intervention development stage has the potential to enhance uptake and make the intervention more applicable to solving real-world problems.

5.7 Summary and next steps

In this chapter, I have described the methodology and findings of my systematic review. The review highlighted that an effective intervention addressing health literacy to improve asthma self-management has yet to be developed and assessed, despite the global importance of the issue. I have thus discovered a gap in evidence about the effectiveness of interventions for people with limited health literacy to improve asthma self-management. The studies I identified were generally at high risk of bias, were poorly reported, lacked theoretical underpinning and were generally ineffective. A robust RCT design is required to focus on clinical effectiveness and the identification of components associated with effective behaviour change.

The challenge for this PhD is to develop a tailored multifaceted asthma self-management intervention for people with limited health literacy. There were several key points learned from this systematic review that can be used to develop an intervention. The next step requires an understanding of what people with limited health literacy and asthma perceive would enable self-management within the Malaysian context. The next chapter reports the
methodology, results and discussion of the adapted Photovoice study approach that I used to achieve my objectives.
Chapter 6  Qualitative study

In the previous chapter, the systematic review demonstrated a significant research gap in studies evaluating the effectiveness of asthma self-management interventions targeted at people with limited health literacy. The review found that behaviour change strategies mainly focused on the individual, and there were gaps in the components being used that a future multi-component intervention could address. To plan for the most effective intervention, I then needed to understand the experience of people with asthma and limited health literacy in Malaysia. I used a qualitative methodology to achieve this. This chapter describes the qualitative method I used, an adapted Photovoice method, and the first of the two analyses; narrative approach to analysis. Figure 12 depicts the work I undertook for the entire PhD programme of work, which is reported in this thesis using the 6SQuID model (Steps 1 to 4) [107]. The red circle refers to the part of the work that I discuss in this chapter.

*Figure 12 Using the 6SQuID model as an overall framework for this PhD.*
The work presented in this chapter has been presented at three conferences (Appendix 6) and published in a peer-reviewed journal. Table 14 outlines the publication related to the qualitative study. This chapter uses the initials of the co-authors to describe their contributions in this PhD programme of work.

**Table 14 Summary of the publication and list of co-authors.**

<table>
<thead>
<tr>
<th>The qualitative findings were published in Health Expectations (Appendix 14).</th>
</tr>
</thead>
</table>

### 6.1 Introduction

#### 6.1.1 The illness narratives

Retelling a story is a process of making sense of an experience and finding meaning in it [154-156]. As a researcher, my role was to identify illness narratives from the experts in such story-telling: those living with asthma and potentially affected by limited health literacy. Illness narratives represent a way to understand what the body experiences through disease and to recover what can be considered lost [156]. People breathe to live – we inhale and exhale, and those without asthma may take such involuntary reflexes for granted. However, people with asthma sometimes struggle to breathe during acute asthma exacerbations, which can interrupt daily living. Repeated disruptions to daily life can impede the reconstruction of meaning and eventually lead to a lack of self-control [157]. Thus, people living with chronic illnesses like asthma may be expected to strive for autonomy to regain control over their illness. According to research on chronic illness, people seek personal autonomy by attempting to control their condition and minimise or prevent disruption to their daily lives [157,158]. People tend to feel empowered when they gain a sense of control of an otherwise unpredictable condition [159], such as acute asthma exacerbations.

Illness narratives are not just about illnesses but also reveal how illness is socially constructed. As previously discussed in Section 2.2.2, limited health
literacy disproportionately affects socially vulnerable populations, such as those with low educational attainment and the socioeconomically deprived [49]. As a result, the challenges of living with asthma may be related not only to people’s health literacy status but also to the various life circumstances that contribute to limited health literacy.

**The sick role**

The embodiment of a sick role is another common element identified within illness narratives, and it is socially constructed [160]; this means that it is assumed that sick people have a duty to recover and, once recovered, will fulfil their social contract by returning to their social obligations. In the early sociology of health and illness literature related to the ‘sick role’, Parsons described sickness as social deviance, posing a problem for individuals with chronic illness, such as asthma, with regard to the social system [160]. Being labelled as ‘sick’ brings with it certain social expectations, rights and responsibilities. A sick role can be about the sick person’s responsibility to identify with this social role and/or being labelled by society as ‘sick’. For a person living with asthma, achieving full recovery and normality may not be possible, as the illness is always present even when it is in a state of dormancy. Problems arise when individuals fail to recognise that they are sick and ignore ‘sick role’ duties, such as attending regular asthma follow-up consultations and using preventer inhalers on a daily basis, as expected of them. People living with asthma may be subjected to prolonged ‘sick’ labelling by others, which can be stigmatising. Parson’s concept was further criticised as it failed to consider individual perspectives and agency [161].

**Illness narrative types**

I used illness narrative types in this analysis (Table 15) to help me see the experience of living with asthma through different lenses. This approach is not intended to simplify their complexity or contribute to the notion that stories are static, but rather to demonstrate how this classification of narrative improves understanding of how participants make sense of and live with their illness [154-156,161]. How people think about and structure their experiences can
impact their daily lives, both physically and emotionally, as well as how they deal with the challenges they face daily. In this chapter, I describe how people sought autonomy by reclaiming their identities in the network of relationships and redefined their interactions with the health system and the environment. The themes identified from the participants’ stories may provide practitioners and researchers with a lens through which they can better understand the meaning of illness experiences for their patients, learn how people living with asthma are affected by life experiences and sufferings, and devise strategies to support them in managing their asthma.

**Table 15 The typology of illness narratives.**

<table>
<thead>
<tr>
<th>Typology</th>
<th>Explanation</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Endurance [154,155,161]</td>
<td>This narrative comes closest to the dominant medical paradigm of how one might live with a chronic condition. The narratives are characterised by the ‘acceptance’ of an adapted life. Life itself is a struggle that may have achievable goals but is less optimistic due to the obstacles people need to overcome to remain healthy.</td>
<td>'I have an illness, but I can manage the symptoms so that I live life despite them.'</td>
</tr>
<tr>
<td>2. Restitution [156]</td>
<td>This account is set in the context of maintaining good health and portrays sickness as temporary physical misery. It dwells on remedies to heal the sickness and restore the physical self to resume social duties. It is the most straightforward narrative to tell and hear.</td>
<td>'I was healthy yesterday, today I am sick, but I will be healthy again tomorrow.'</td>
</tr>
<tr>
<td>3. Chaos [156]</td>
<td>This is the least heard narrative because it is a life story that does not improve or is ‘frozen’. The story can only make sense if abstractions are made, but this can only happen if chaos is made coherent, which is often difficult to achieve. Telling and hearing a chaotic narrative provoked negative emotion. It is an example of anti-narrative, where narratives have no apparent cause and are not connected through time.</td>
<td>'Things took place. It happened later on. That happened. Again, this occurred.'</td>
</tr>
</tbody>
</table>
6.1.2 The context for this qualitative study

The qualitative study was conducted in Klang, an urban district in central Malaysia (a detailed description of Klang District can be found in Section 1.1). I conducted the qualitative study at four public primary care clinics in the Klang District. These clinics cover more than 50% of the population. In an urban area, the socioeconomically disadvantaged population is more likely to use public health services [162]. My PhD programme of work in the Klang District focused on people with asthma and limited health literacy. People with limited health literacy tend to be socioeconomically vulnerable [49]. A previous cross-sectional study I conducted, prior to this PhD, among people with asthma in Klang’s primary care clinics reported that close to two thirds of patients with asthma in this setting have limited health literacy and that they tend to be in the socially disadvantaged group (e.g., they have lower educational attainment and are of lower socioeconomic status) [1].

As outlined in Section 2.2.3, limited health literacy is associated with improper use of inhalers, poor asthma knowledge [68] and increased utilisation of emergency care and hospitalisation for asthma exacerbations [47,68,163]. People with asthma need to interpret their symptoms and act on them, including adhering to medication, adjusting treatment and/or deciding to seek advice in the event of deterioration [69,164]. Without the proper support, this may be challenging for people with limited health literacy [87,164]. Furthermore, being socially vulnerable puts people with asthma who have limited health literacy at risk of being pushed to the margins of the healthcare system and being disadvantaged by health disparities. For example, someone who has trouble understanding the standard written asthma action plan will find it challenging to manage their symptoms according to guideline-recommended care. Social vulnerability is not an individual’s intrinsic characteristic; instead, it is a marker of life circumstances, such as limited access to quality education, learning differences and linguistic isolation.
6.1.3 The rationale for the qualitative methodology

To explore experiences of living with asthma among people with limited health literacy in Malaysia, I elaborated the rationale for four crucial aspects, which are discussed in this section:

i) Why a qualitative study design was chosen.

ii) In-depth interviews versus focus-group discussion.

iii) Why it was decided to use Photovoice.

iv) Why and how Photovoice needed to be adapted to the Malaysian context.

Qualitative methodology is appropriate to explore perceptions and illness stories

I used qualitative methods to explore the subjective experiences of living with asthma among people with limited health literacy in Malaysia. A qualitative exploration of the subject is the best way to learn about the study participants’ perspectives, experiences and ideas, because this approach does not have a set agenda and is open to new directions and ideas, allowing themes to emerge from the data.

For this purpose, the interviews could help me understand how people with asthma who have limited health literacy make sense of their disease and their care through their oral accounts of events. To feel supported, participants need to feel that they are being heard and empowered so that they feel safe and comfortable discussing issues that matter to them. For this purpose, I adapted the Photovoice methodology to give them the means to discuss, in ways other than verbal, the social issues and inequalities they may face. The use of photographic methods to understand self-management practice for asthma among people with limited health literacy can be epistemologically enriching and a powerful avenue for gaining a comprehensive understanding of how people come to understand and experience illness. Photographs taken by the participants themselves aided in story-telling and added a visual dimension to the stories told. The process also allowed the participants to set the agenda by choosing what they photographed. Such qualitative approaches help to
improve understanding by combining language, concepts, words and images to produce evidence [165].

**Interviews were more appropriate than focus group discussion in the context of this study**

I used in-depth interviews as a fundamental approach for creating rapport and fostering trust with potentially socially vulnerable participants. Using in-depth interviews may provide a safe space for participants to speak about their psychosocial circumstances without worrying about judgements or opinions of other participants. Because Malaysia is a multicultural and multilingual society, I needed to navigate the differences of participants’ ethnicity and spoken languages. In Malaysia (and many other societies), these differences may contribute to perceived differences in power and privilege among the different ethnicities. I was aware that these differences might be perceived to hinder the understanding of health beliefs and cultures in research interviews [166], and thus I made the decision to use one-on-one engagements throughout the study process.

**An adapted arts-based method (Photovoice) offers non-verbal options which may give voice to people with limited health literacy**

Photovoice is fundamentally transformative. The research process, which is participant-led, is designed to give people a means of expression by having them take, select, frame and discuss photographs about a topic that is important to them. Crucially, in the original Photovoice methodology, the community creates a collective space to reframe, own and present the issue to communicate their concerns to policy- and decision-makers [167]. The Photovoice method was developed based on three theoretical understandings. The first is Freire’s approach to critical education, whereby visual images act as a tool to enable a person to look at the world and its problems critically and engage in a dialogical encounter with others to identify common themes [168]. The second theoretical basis derives from the feminist movement [169], whereby feminist theory sheds light on male dominance in participatory research. Feminism contests gender oppression and patriarchy in research.
Its theoretical debates have focused on diversity (involvement of women), the inclusion of gender issues and shifting the lens of research away from the dominant views of social reality (male dominance) in participatory research [169]. The third understanding of Photovoice is community-based, whereby a camera is used as a tool so that ‘ordinary’ people, who might otherwise be incapable of bringing about change, can record and catalyse transformation in the community [170]. To date, Photovoice has not been used in asthma research for participants to critically reflect on living with asthma and to empower them to discuss issues around decision-making that matter to them [171,172].

*The adaptation of Photovoice methodology within this study: the need to reflect on a multicultural society*

Photovoice is a relatively new research method in Malaysia; thus, in order to conduct Photovoice within the community, I needed to be mindful of cultural norms [173,174], listen to views from the PPI members (see Section 6.2.7), and implement the method within the timeline and resources of my PhD. Therefore, I adapted the methodology, learning from other studies in high-income settings [175,176] and Africa [177,178].

The original Photovoice methodology described by Wang and Burris [167] was a sequential, group-based process. The process started with the first engagement, whereby the research was explained to recruited participants to help them understand the assignment and train them in a group to take the photographs. Then, within a given timeline, participants were given the freedom to take photographs as individuals; however, only key photographs were chosen by the group, and these key photographs were used to stimulate a group discussion of the personal and community issues that mattered to the group [167]. This was followed by group dialogue with policy-makers using key photographs and, finally, a workshop on participants’ evaluation of the process [167].

I adapted Photovoice using several strategies. I used one-on-one engagements throughout my study process, and I also used initial in-depth
interviews, for the reasons stated previously. I started the study approach with an initial in-depth qualitative interview. This initial interview was an appropriate strategy to secure initial engagement, gain community entry and foster relationships and trust among the research participants. During the initial interview, I introduced individual participants to all the study stages, including the Photovoice stage, and invited each interviewee to take part. If the interviewee was interested in taking part in all the stages, I trained them to use the camera at the end of the initial interview and discussed the ethics of photo-taking with them individually. They were then given two weeks to complete the photo-taking task, and we met again after the films had been developed to discuss all of the photographs. The details of the study process are described in Section 6.3. Figure 13 illustrates Wang and Burris’ stages [167] alongside the Photovoice process used in my study.

My adaptations have advantages and disadvantages, which are discussed in greater detail later in this chapter under the Discussion (Section 6.5.2).

*Figure 13 Comparison of Photovoice process in Wang and Burris (1997) with the adaptation used in this study.*
6.2 Objectives of this qualitative study

6.2.1 Objectives

To explore subjective experiences of living with asthma among people with limited health literacy in Malaysia:

a. to explore the experience of living with asthma,

b. to explore the role of health literacy in understanding asthma and how it influences decisions about self-management, and

c. to identify barriers to using evidence-based self-management plans among people with limited health literacy and to identify how the use of such plans can be supported.

6.3 Methodology

This study received ethics approval from the Medical Research and Ethics Committee of the Ministry of Health, Malaysia (ID: NMRR-18-2113-42322) and sponsorship approval by the Academic and Clinical Central Office for Research and Development (ACCORD; ID: AC18113).

6.3.1 Study design

Qualitative research methods were employed, and I took the following steps to conduct the study. There were three stages to this study (Figure 14). Stage 1 involved one-to-one in-depth qualitative interviews, Stage 2 involved training and photo-taking activity, and Stage 3 involved one-to-one Photovoice discussions with the sub-set of participants who successfully took photos.
Initial one-to-one interviews were conducted with the aid of a semi-structured interview guide (Appendix 15), which incorporated elements of theories that could help identify factors affecting health decision-making, such as knowledge, beliefs, attitudes, competency, readiness for self-care, and broader psychosocial factors that may influence this behaviour [36,180-183]. All participants were invited to take part in the Photovoice component. Those who agreed went on to take part in a two-week photo-taking activity. They were given training in the use of a 27-roll disposable camera and the ethics of photo-taking. The photographs were then used during a second interview (the photo-interview).

6.3.2 Setting and recruitment of participants

The study was conducted at four primary health clinics in Klang District, a central region of Malaysia (see Section 1.1 for details about Klang District). Table 16 provides a description of Malaysia’s healthcare system and its multicultural society. These clinics were chosen to reflect a range of urban, suburban and rural populations to enable recruitment of a broad range of participants. Recruitment of participants and data collection ran between February 2019 and August 2019. Advertisements and information about the study were placed at the clinic’s registration counter and in the waiting room,
directing people to a ‘RESPIRE’ research stand within each clinic and providing my contact details, if I was not present at the time. I explained the study to potentially interested participants (face-to-face or by telephone, depending on how participants made contact with me) and assessed eligibility. Video information sheets helped potential participants visualise the research process and understand what was involved, regardless of reading ability, and thus make an informed decision about participation. The video, alongside other study documents, were deposited online so that participants could watch it in their own time (https://www.ed.ac.uk/usher/respire/health-literacy-asthma-malaysia/about-the-study) before they gave written consent.

**Table 16 Multicultural Malaysia and the health system.**

<table>
<thead>
<tr>
<th>The health system</th>
<th>Multiracial and multilingual Malaysia</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Malaysia has both public and private healthcare systems.</td>
<td>• Malaysia is a multiracial country comprising three main ethnic groups: Malays, Chinese and Indians, each with their own culture and language.</td>
</tr>
<tr>
<td>• The Government heavily funds the public health sector through taxation. The private sector is a ‘fee for service’ model often covered by insurance policies.</td>
<td>• The national language, Malay, is used as the main medium of instruction in both primary and secondary national schools.</td>
</tr>
<tr>
<td>• The Government provides primary, secondary and tertiary care for the population. National Referral Centres provide specialised care and support the primary care service [93].</td>
<td>• English is learned as a second language.</td>
</tr>
<tr>
<td>• In the public health sector, services are free with co-payment ranging from MYR1 (GBP 0.17) to MYR 5 (GBP 0.87) for outpatient services and MYR 3 (GBP 0.54) per day of admission [90]. The maximum MYR 5 (GBP 0.87) fee is for outpatient specialist consultation [90].</td>
<td>• At the primary school level, schools may also offer Mandarin and Tamil mediums of instruction.</td>
</tr>
</tbody>
</table>

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The study population were adult patients (18 years and over) with physician-diagnosed asthma, who were currently receiving asthma treatment and who attended care at any of the four centres. In this study, I recruited patients with
limited health literacy, which I defined as a score of less than 33 based on an assessment of their health literacy level using a validated Malay-language version of the HLS [43]. Asthma control was assessed using the asthma control questionnaire (ACQ) [122,184]. In Table 17, I describe the screening tools used, the ACQ and HLS. I purposively sampled participants with a maximum variation in terms of demographic (age, gender and ethnicity) and asthma control. Those who were eligible were given two weeks to decide on participating. For those who agreed to participate, an initial interview date and time were arranged at the most convenient clinic for the patient.

**Table 17 Performance of the screening tools.**

<table>
<thead>
<tr>
<th>Asthma control questionnaire, ACQ</th>
<th>Health literacy scale, HLS-Q47</th>
</tr>
</thead>
<tbody>
<tr>
<td>The ACQ, which contains five items, is a validated and translated tool to measure the adequacy of asthma treatment [122,184].</td>
<td>The HLS, which contains 47 items, is a validated and translated tool to measure health literacy [40,43].</td>
</tr>
<tr>
<td>A 7-point scale is used to grade the severity level (0 = no impairment; 6 = maximum impairment) [184].</td>
<td>Each item’s perceived difficulty is rated on a 4-point Likert scale (1 = very difficult, 2 = difficult, 3 = easy, and 4 = very easy), with a possible lowest mean score of 1 and a possible highest mean score of 4.</td>
</tr>
<tr>
<td>Patients with a score below 1.0 will have adequately controlled asthma; for patients with a score above 1.0, their asthma will not be well controlled. However, to be confident that a patient has well-controlled asthma, the optimal cut-off point is 0.75 (negative predictive value = 0.85), and for inadequately controlled asthma, the optimal cut-off point is 1.50 (positive predictive value = 0.88) [185].</td>
<td>Mean score is calculated and general health literacy is then formulated using an index score, ( \text{Index} = (\text{mean} - 1) \times (50/3) ) [40]. All scores were transformed to a unified metric (Index) with a minimum of 0 and a maximum of 50, where 0 represents ‘the least possible’ and 50 represents ‘the best possible’ health literacy score [40]. This scale categorises the population into dichotomised categories of ‘limited’ or ‘adequate’ health literacy levels where limited health literacy is classified if the Index is &lt;33 points [40].</td>
</tr>
</tbody>
</table>
The short version ACQ (symptoms alone – ACQ version) was used. This questionnaire assesses the patient’s asthma control by ascertaining the patient’s experiences during the previous week in response to the five questions (night time waking, symptoms on waking, activity limitation, shortness of breath and wheeze).

There is a good internal consistency of these five questions (Cronbach $\alpha = 0.98$).

The HLS is based on a conceptual model of health literacy and measures four competencies to deal with health-relevant information (access/obtain, understand, appraise/judge/evaluate and apply/use health information) in three domains: health care, disease prevention and health promotion [40].

There is a good internal consistency of these 47 questions (Cronbach $\alpha = 0.97$).

### 6.3.3 Data collection

Written informed consent was obtained before each activity and for each stage. In Stage 1, each participant was invited for an initial in-depth, semi-structured interview. The photo-taking activity (Stages 2 and 3) was offered to everyone who participated in the initial interview. For those who consented to participate in Stages 2 and 3, I conducted a 30-minute training session on using a disposable camera and photo-taking ethics (e.g., asking permission to take photographs of others) after the initial interview. I provided a guide on how to use a disposable camera and how to take care of it. Each participant who agreed to participate in the photo-taking activity was given a disposable camera containing a 27-exposure film roll, with which to complete the activity in two weeks. They were allowed to take as many photographs as they wished but were asked to take twice (as backup, in case of low quality) any photograph they felt was vital. Participants were given guidance about what photographs to take (Table 18) and an infographic format was given for each participant to take home (see Appendix 16 for example).

<table>
<thead>
<tr>
<th><strong>Table 18 Guidance on the focus of the photo-taking activity.</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Please take pictures that show</td>
</tr>
<tr>
<td>What is it like to live with asthma?</td>
</tr>
<tr>
<td>What helps you, or what makes it more challenging to live with asthma?</td>
</tr>
<tr>
<td>How do you learn about asthma, and where do you get information about it?</td>
</tr>
</tbody>
</table>
Using an interview guide (Appendix 15), the initial interviews began with a general discussion about personal experiences living with asthma. Participants’ flow of conversation was not restricted by the guide, which was used flexibly to ensure a smooth discussion. I conducted the interviews with the assistance of an interpreter, Thivya Periasamy (TP). I am fluent in English and Malay; TP is fluent in Tamil and Mandarin and translated as needed. The choice of language was left to participants' preference, and they could move between languages if desired.

I arranged for film development, digitalising and printing photographs from returned cameras in Stage 2, preparing for Stage 3 interviews. I asked participants for consent on how they wished individual photos to be used. For this purpose, the photographs were displayed in hardcopy format, and participants were given three options for each photograph:

i) the photograph may be shared with the researcher and reproduced in publications with a caption of the participant’s choosing;

ii) the photograph (hardcopy form) may be shared with the researcher but may not be reproduced;

iii) the photograph may not be shared with the researcher or reproduced.

This process was vital to allow participants to understand the use and implication of reproducing photographs and to reflect and choose photographs they would allow to be reproduced [186].

All photo-interviews in Stage 3 were individual interviews. I started the interview using the photographs that the participant had agreed to share with me; TP translated when necessary. Participants were encouraged to narrate and reflect on the story of living with asthma using these photographs and to discuss any key issues that mattered to them. During the interview, participants were asked if there were any situations that they decided not to capture during the photo-taking activity. I encouraged the participants to explain the reasons behind these decisions (or why they decided not to share specific photographs with the researcher), but they were free not to explain
their decisions. All interviews (initial interviews and photo-interviews) were audio-recorded using an encrypted audio-recorder. Field notes were written during each interview to keep track of observation, thoughts, insights and reflections.

6.3.4 Data handling and translation

Interview recordings were reviewed, and the transcriptions process began in parallel to the ongoing interviews and photo-activities, so that insights and ideas gained could inform subsequent interviews. All recorded interviews were transcribed verbatim in the original language, checked for quality and accuracy and anonymised. All transcripts were translated into English using back-to-back translation methods [187]. Transcribing and translations of Mandarin and Tamil languages transcripts to English were done by native speakers and I translated *Bahasa Malaysia* language transcripts (see examples of the translation process in Appendix 17). All transcripts were back-translated by linguists to ensure accuracy. Where it was not possible to translate metaphors, idioms or culturally specific expressions into English, the original language was maintained, and explanatory footnotes provided [187-189]. The later initial interviews were conducted concurrently with the early photo-interviews; thus, the insights and themes from the two qualitative methods iteratively influenced each other. The photo-interviews both served as an extension of, and enabled an in-depth understanding of, the initial interviews. The presence (or absence) of photographs allowed for discussion of other topics important to the participants, such as relationships and norms, in all interviews.

6.3.5 Data analysis

The qualitative work, as a whole, aimed to offer an analysis of the accounts of experiences living with asthma and limited health literacy. I used two analytical approaches to address the research objectives: a narrative approach (described in this chapter) and a health literacy framework analysis (Chapter 7).
A narrative approach to analysis

I employed Riessman's narrative analysis approach, which focuses on what individuals say rather than how they say it [190]. In this analysis, stories or narrations are analysed and re-told in a framework that will make sense to readers, paying particular attention to key elements such as time, place, plot and scene [191,192]. In my analysis aimed at answering objective 2 (a), I used a narrative approach to explore the lived experience of people with asthma and limited health literacy in Malaysia. I began my analysis by familiarising myself with the contents, reading and re-reading the interviews [190]. The accounts were read with the question in mind: What kind of narrative is this? In answering this question, I read, re-read, summarised each story, and focused on what each participant told me about their experiences. Each transcript was reviewed, along with the accompanying photographs and the participant’s description of the photographs. The photographs were effective tools to gain insights into the story being told and to support further interviews. The analysis focused primarily on what was being said in the interviews. For participants who took part in both initial and photo-interviews, these interview transcripts were analysed together for each participant. Categorising the stories told by participants into specific narrative types allowed a clearer view of the overall story being told and permitted recognition of commonalities and differences among stories of the various participants. See Appendix 18 for working examples of the narrative analysis (exploring narrative types).

Next, I reviewed and analysed the completed transcripts inductively for themes within the narratives. At the start, SSG/PYL and I reviewed two transcripts independently and compared our findings to ensure rigour in interpretation. Then, I continued to review and analyse the rest of the transcripts for themes in discussion with IY/HP. The thematic elements were identified initially within each participant’s narrative, and these themes were then compared with those of other participants. This approach offers a bottom-up, in-depth thematic analysis to find commonalities and differences when the themes are interpreted in the context of the narrative text [190]. In addition, it provides
knowledge of key aspects of the experiences of living with asthma among people with limited health literacy, as experienced by the participants of this study and based on my interpretations of these experiences. See Appendix 19 for working examples of the narrative analysis (exploring themes).

The supervisory team came from diverse clinical, health, and social research backgrounds, ensuring rigour in interpreting the data. As an interpretative method, a narrative approach to analysis helps explain the meaning of living with asthma and the factors influencing decisions about self-management within the social context as participants understand it. Compared to thematic analysis, which involves extracting short quotes from the stories and potentially losing their context, recognising the themes in narrative analysis leaves the narrative intact [191]. The data collection and data analysis stages overlapped and were conducted iteratively. The data were organised using QSR NVivo 11 qualitative data analysis software.

6.3.6 Trustworthiness of research

Trustworthiness refers to the degree of confidence in data, interpretation and methods used to ensure the quality of a study [191]. Lincoln and Guba (1985, 1989) developed four criteria to evaluate the trustworthiness of a qualitative work [193,194]. These are widely known criteria and remain a gold standard that many qualitative researchers use [165,191]. The four criteria are credibility, transferability, dependability and conformability. Table 19 summarises the definitions of these terms and how I used them to ensure the trustworthiness of the qualitative study.

**Table 19 Summary of terms and how the criteria were addressed in this study.**

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Comparative term used in a quantitative study</th>
<th>Research strategy</th>
<th>Techniques to ensure trustworthiness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Credibility</td>
<td>Internal validity</td>
<td>1. Field notes/memo</td>
<td></td>
</tr>
</tbody>
</table>
This concept examines the correspondence between what participants say and how the researchers represent these viewpoints.

<table>
<thead>
<tr>
<th>Transferability</th>
<th>External validity</th>
<th>1. Data display</th>
<th>1. Sampling strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>This concept refers to the generalisability of inquiry. It asks to what degree the study findings can be generalised or applied to other individuals, groups, contexts or settings.</td>
<td></td>
<td>2. Simultaneous literature review</td>
<td>2. Thick descriptions of the context, setting and people studied.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Dependability</th>
<th>Reliability</th>
<th>1. Field notes/memo</th>
<th>1. Audit trail of process logs</th>
</tr>
</thead>
<tbody>
<tr>
<td>This concept refers to the consistency of the data over time, across researchers and across methods.</td>
<td></td>
<td>2. Tape recorder</td>
<td>2. Peer review</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Auditing preliminary themes/analysis</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Conformability</th>
<th>Objectivity</th>
<th>1. Field notes/memo</th>
<th>1. Audit trail</th>
</tr>
</thead>
<tbody>
<tr>
<td>This concept refers to the degree to which the findings are determined by the respondents and conditions of the inquiry and not by the interest and perspectives of the inquirer.</td>
<td></td>
<td></td>
<td>2. Peer review</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3. Member checking</td>
</tr>
</tbody>
</table>

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**Prolonged engagement**

Overall, it took nearly eight months from the initial approach into the community to the final communication with interview participants. The initial qualitative interview was critical in gaining access to the community and enhancing long-term engagement for those involved in Photovoice activities, and it was important for building rapport and trust with the participants who went on to engage with the Photovoice activities. The initial qualitative interviews and subsequent Photovoice activities enabled the participants and I to interact for extended periods through telephone calls, messaging and face-to-face meetings for recruitment, interviews and preliminary analysis. The relationship established by the initial interview allowed the subsequent photo-interview to
build on it, shaping the data collection process. It allowed for more probing, and the photographs provided alternative creative spaces for the participants’ in-depth descriptions.

**Member checking**

During these meetings, I checked the accuracy of the descriptions accompanying the photographs and inquired about the interview’s preliminary themes – a strategy known as member checking. I did not return to the original transcripts with the participants because I was more interested in their perspectives on the preliminary analysis.

**Peer review**

Recorded interviews, transcripts, photographs and field notes were the sources used to generate the findings. The findings were generated in collaboration with a group of researchers from various clinical and social research backgrounds. The multidisciplinary approach to analysis was enabled by their diverse experiences of cultural and social contexts of health practice. In addition, four abstracts from this qualitative study have been presented orally or as posters at seminars and conferences (see Appendix 6 for examples). Feedback and comments from these audiences contributed to the interpretation of the data and further discussion. Two manuscripts have been written from this qualitative study, in which one was published [179]. The reviewers’ comments have helped to ensure the claims and arguments for this study are valid and scholarly.

**Reflexivity**

Reflexivity refers to the process of critically reflecting on oneself as a researcher or as a human being acting as an instrument. It backs up a qualitative researcher’s claims about the nature of knowledge and the integrity of knowledge. According to Sandelowski (2000), ‘qualitative work is produced not through any “pure” use of a method, but through the use of methods that are variously textured, toned, and hued’ [195]. As a researcher, I played a critical role in generating, shaping, and analysing the data; thus, objective
distance from the research is impossible. As a result, I address reflexivity concerns to provide transparency of the research process and ensure the quality of the data. While this study was conducted in Malaysia, it was funded by RESPIRE, a National Institute of Health Research (NIHR) Global Health Unit to improve respiratory health. However, I proposed, developed and conducted this project in discussion with the researchers from Malaysia, ensuring understanding of local issues and resonance with local socio-cultural context.

I am a family physician with more than ten years of experience working in the Malaysian primary care setting. As a clinician, I acknowledge the potential difference in hierarchical relations of power between the researchers and the participants, especially in creating rapport. Therefore, I used a strategy to introduce myself as a family physician during my early encounters with the potential participants and during data collection. Furthermore, at each indepth interview, I emphasised my position as a researcher in understanding participants' experiences living with asthma. In addition, regular reflective sessions with my local supervisors (SSG or PYL) helped me remain neutral and avoid judgemental cues during data collection.

The initial interview was an essential step for fostering trust with the participants for research. In this study, when comparing the initial interviews and photo-discussions, it was observed that the responses during the initial interviews were sometimes brief or guarded, especially around the topic of adherence to inhaler therapy and regularly attending asthma reviews. This observation suggests a bias potential due to my being identified as a healthcare professional. Some participants initially seemed to evade the topic of their negative experiences engaging with healthcare professionals or the system. Unequal power may make it challenging to elicit descriptions of social practices, explore personal issues such as identities, and understand how adults with limited health literacy live with asthma. Participants' elaborations on such issues sometimes seemed to change during subsequent interviews, maybe because of better rapport and trust with the researcher. They provided
more open narratives of their health practices and life experiences, for example, their approach to symptom control or experiences with healthcare professionals.

The qualitative method questioned how participants saw people, things and spaces around them. Some people found that ‘rebuilding’ their living conditions or encountering life situations that might affect their asthma was a positive experience because it opened up previously untapped ideas and insights. Some participants were emotional, especially when responding to the questions; ‘How can you be supported?’ and ‘What cannot be photographed?’, which required a great deal of empathy and verbal and nonverbal communication skills. Raw emotions have a variety of effects on people. In light of this, I extended the time after the interview, if the participant desired, to bring the discussion to a close. Participants were offered referral to professional assistance if they wished, although no participant took this up. I allowed myself to debrief by discussing research experiences with the research team (SSG/PYL/IY/HP) through telephone calls or e-mails while maintaining participants’ confidentiality.

**Sampling strategies**

The study was first promoted in February 2019 during a community health event where I spoke about asthma and how it affects life. Participants from the community health event who expressed interest in the qualitative study and were eligible to participate were recruited, and a snowball effect ensued. Other participants were directed to the study booth in practice by clinic members, notably health practitioners. I purposefully selected participants from a pool of volunteers with a wide range of demographics (age, gender and ethnicity) and asthma control characteristics. I administered the HLS to ensure that I captured the perspectives of people with limited health literacy living with asthma.
**Thick descriptions of the context, setting, and people studied**

In this study, I obtained detailed descriptions of people living with asthma and limited health literacy through narratives. In Section 2.4, I described the Malaysian context and setting in detail. I also include the description of the characteristics of the participants in this chapter (Section 6.3.1).

**Audit trail of process logs**

In my research journal, I documented two aspects of the research: audit trails for decision making and field notes to capture my reflections on the interviews and the research process as a whole. I kept a decision trail from the study’s inception. Initially, I intended for this to be a qualitative study based on interviews. However, my supervisor, HP, suggested that a more creative approach to uncovering issues among people living with asthma and limited health literacy would be worth exploring. Supported by IY, I discovered literature on using adapted Photovoice study design for a marginalised population, which seemed likely to be a good approach for empowering people to articulate their experiences on their own terms.

I compiled my reflections after each interview in discussion with SSG/PYL, made memos on the issues which I had not included in my initial topic guide, and brought these issues forward in the following interviews. For example, during the fourth interview, a participant described how breathing difficulties affect intimate relationships and how she mitigates this issue. I brought this up as a prompt in subsequent interviewees, when appropriate.

**6.3.7 Patient and public involvement (PPI)**

Photovoice is a relatively new research method in Malaysia; thus, views from the PPI members were particularly valuable. The PPI members who took part in this discussion were part of the larger PPI group within RESPIRE Malaysia. I conducted a discussion with three PPI colleagues who also received asthma care at the study practice, to invite their comments about the methodology. They were initially concerned about this unfamiliar research method, the ethical issues related to privacy (e.g., photographs), and people’s willingness
to share photographs of their lives with others. We discussed the fact that sharing information about one’s health may not be a norm within the local socio-cultural ecology. Some may consider it bad luck, which may be a barrier to recruitment. Despite these initial concerns, after discussion, they agreed that this was an exciting methodology and suggested introducing the research members and project to the clinic’s users through the primary care clinic’s community activities.

As suggested by the PPI discussion, I prepared a talk on raising awareness about asthma and delivered it to members of the local community at one of the primary care clinics in Klang, and I introduced the Photovoice research at the end of the presentation. This engagement activity was an essential point of contact with potential participants and encouraged involvement. Other suggestions from the PPI members were to extend the initial timeframe from one week to one month. I was concerned about the retention and recall bias of a month-long timeframe, so I opted for two weeks for participants to complete the photo-taking tasks.

6.4 Results
Between February to August 2019, a total of 32 participants with asthma approached and agreed to be part of the study. Four participants who had adequate health literacy were excluded, and two participants could not commit to the study due to time and work commitment. Twenty-six participants provided initial interviews. Of these, only 12 participants agreed to participate in the Photovoice; and only eight completed the photo-taking activities. Reasons for non-participation in the photo activities (Stages 2 and 3) included time constraints and hospitalisation for a severe exacerbation during the study recruitment. In total, 34 in-depth interviews were conducted: 26 initial interviews and eight photo-interviews.

6.4.1 Description of participants
Table 20 summarises the participants’ characteristics. Most participants (23 out of 26) had uncontrolled asthma based on asthma control screening.
Table 20 Characteristics of participants.

<table>
<thead>
<tr>
<th>Profile</th>
<th>Sub-profile</th>
<th>Completed initial interview (n = 26)</th>
<th>Completed photo-interview (n = 8)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td></td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td>Female</td>
<td></td>
<td>18</td>
<td>6</td>
</tr>
<tr>
<td>Age category (years)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean age = 48.6</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18–27</td>
<td></td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>28–37</td>
<td></td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>38–47</td>
<td></td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>48–57</td>
<td></td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>58–67</td>
<td></td>
<td>7</td>
<td>–</td>
</tr>
<tr>
<td>68–77</td>
<td></td>
<td>2</td>
<td>–</td>
</tr>
<tr>
<td>78–87</td>
<td></td>
<td>1</td>
<td>–</td>
</tr>
<tr>
<td>Self-assigned ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Malay</td>
<td></td>
<td>15</td>
<td>5</td>
</tr>
<tr>
<td>Chinese</td>
<td></td>
<td>5</td>
<td>–</td>
</tr>
<tr>
<td>Indian</td>
<td></td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>ACQ score†</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean score</td>
<td></td>
<td>1.8</td>
<td>1.6</td>
</tr>
<tr>
<td>Controlled, n (%)</td>
<td></td>
<td>3 (11.5)</td>
<td>2 (25)</td>
</tr>
<tr>
<td>Uncontrolled, n (%)</td>
<td></td>
<td>23 (88.5)</td>
<td>6 (75)</td>
</tr>
<tr>
<td>HL score</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean‡</td>
<td></td>
<td>23.7</td>
<td>25</td>
</tr>
</tbody>
</table>

NOTES: Score less than 0.75 = well-controlled†; mean less than 33 = limited health literacy‡

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In this study, participants’ health literacy levels were screened before the interview, and they were unaware of their health literacy status prior to this. Even before the screening, the vast majority of participants shared a common agreement that they ‘did not know much about asthma’, and thus, they were not surprised or intimidated when the screening results were explained. Almost all participants described their asthma control as well controlled, although their objective scores showed that most had poorly controlled asthma.

Promoting the community voice

As part of the adapted Photovoice design, I arranged a small-scale exhibition at a scientific meeting conducted in Malaysia attended by all colleagues from
the RESPIRE Global Unit (https://www.ed.ac.uk/usher/respire), including senior investigators across all the partner countries and the stakeholders from the Malaysian health system. The details of this event are described in Section 10.2.5, as part of stakeholder engagement work.

6.4.2 Presentation of findings

In this analysis, three themes were identified:

i) Asthma is a life story;

ii) Reclaiming identity in the network of relationships; and

iii) Redefining interactions with the health system and environment.

The concept of autonomy was central to all three themes; participants expressed a desire for power in order to have control over making health decisions. Table 21 provides a summary of the themes. To protect the participants’ anonymity, pseudonyms are used. In this section, I use the term reliever inhaler (inhaled beta-2 agonists or salbutamol) and preventer inhaler (ICS) to describe the inhalers.

Table 21 Summary of overall themes.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asthma is a life story</td>
<td>Living with asthma symptoms illustrated through illness narrative typology</td>
</tr>
<tr>
<td></td>
<td>The physical and emotional burden of living with chronic symptoms</td>
</tr>
<tr>
<td></td>
<td>Coping mechanisms</td>
</tr>
<tr>
<td>Reclaiming identity in the network of everyday relationships</td>
<td>Negotiating occupational identities</td>
</tr>
<tr>
<td></td>
<td>Managing social expectations</td>
</tr>
<tr>
<td>Redefining interactions with the health system and environment</td>
<td>Experience with medical care influenced engagement</td>
</tr>
<tr>
<td></td>
<td>The environmental challenge of managing one’s asthma</td>
</tr>
</tbody>
</table>

Theme 1: Asthma is a life story

I used three different types of illness narrative described by Frank [156,161], Crossley et al. [154] and Thornhill et al. [155]: endurance [154,155], restitution [156] and chaos [156] (see summary in Table 15). These narrative types act
as lenses to understand participants’ descriptions of their lived experiences with asthma. The classification aids in elucidating the common and unique challenges that participants faced across all groups of narratives. Participants described the physical and emotional burdens associated with living with asthma symptoms across all narrative types. Participants whose experiences corresponded to the chaos narrative found it impossible to negotiate their way out of the difficulties they faced. However, in other participant groups (endurance and restitution narratives), participants described how they coped with challenges and reported how they navigated around these challenges in their own unique ways.

- **Endurance narratives**

The endurance narrative maps onto previously identified narrative genres, such as the ‘normalising story’ identified by Crossley et al. [154] and the narrative of acceptance described by Frank and subsequently by Thornhill et al. [155,161]. The narrative is characterised by the story of ‘acceptance’ of an adapted life, and people are often described as being minimally affected by their diagnosis. Strategies for minimising the impact of a diagnosis on daily life are frequently devised [154]. The strategies include self-description and metaphors to imply that one is carrying on as usual, being realistic about the situation, accepting medical therapies to control the disease, and not allowing the challenges to get the better of one [154,155,161]. The fundamental backdrop of the endurance narrative is a life with struggles and obstacles that may have achievable goals [155]. The endurance narrative comes closest to the dominant medical paradigm of how one might live with a chronic condition; this narrative suggests that the chronic condition plays a crucial role in the construction of meaning in recovery from acute ill-health episodes and that accepting these experiences is a part of a chronic illness spectrum [154,155,161]. The identification of this narrative in this study is essential to illustrate the ways participants find meaning and make sense of their illness experiences, how they were affected physically and emotionally, and how they cope with the challenges of living with their condition.
The endurance narrative was the most common narrative observed among participants in this study, who described a life-long condition that can only be controlled rather than cured. Participants of this study whose interviews followed the patterns of the endurance narrative described a period of struggle but with attainable goals. In terms of asthma exacerbation history, these participants were likely to report a history of severe exacerbations during the early years of their diagnosis, which required up to five episodes of emergency care or hospital admissions in a year. However, the exacerbations tended to reduce over the years. Most of these participants had had one or two severe exacerbations in the year before the interview. Instead of rejecting a sick role [160], participants embraced it, adjusted to life with asthma and accepted that they would never be free of asthma. However, many of the participants in this group described living with the emotional burden of asthma, and a few would further describe the physical pain they experienced in acute asthma exacerbations. In general, participants whose interviews followed the endurance narrative were more proactive in developing strategies to deal with asthma symptoms than other participants.

One aspect of the endurance narrative was how people managed their asthma on a day-to-day basis in the context of the therapies used. While the strategies may vary, from complementary and alternative medicine to prescribed inhalers, participants in this group expressed a preference for combining these options rather than choosing one over the other. In terms of inhaler therapy, there was a common understanding across all participants that reliever therapy is far superior to the preventer therapy as it ‘stopped’ or ‘lessened’ an acute asthma exacerbation. Only a small group of participants described daily use of preventer therapy, a choice based on previous experiences of success in managing their symptoms despite triggers by using a daily preventer. They described how they sought to adhere as best they could to prescribed treatments, including life-long adjustments to control asthma symptoms. One example is Habibah, a retiree. She was diagnosed with asthma in her mid-20s, when she struggled with daily night coughs associated with frequent exacerbations requiring emergency care in the first few years of diagnosis.
Over time, Habibah’s asthma symptoms, including night coughs, were eventually controlled with a step-wise therapeutic approach. Habibah shared her understanding of asthma and her perseverance in inhaler use:

_It is not possible to be cured of asthma. I definitely can’t; there is no end to this. I can only control my asthma by taking my daily inhalers and seeing the doctors for asthma appointments. It’s the new routine I’ve lived with since many years ago. I’ve accepted that. [...] I can’t control being too emotional, stressed, or the rainy season where it can get cold. These are the things that can make me cough at night. I can’t control these. But what I can control is taking my inhaler every day. And if I do that, even if it’s cold, the [asthma] attack does not come easily._ [Habibah, 73-year-old Malay woman]

In the above example, Habibah recalls making lifestyle changes and diligently taking her daily inhalers because she realised that this was the only therapy that could prevent flare-ups caused by various factors. Like Habibah, other participants who shared their life stories described how they recognised the need to continuously manage their condition and that adherence to drugs was the only aspect of asthma that they could control and ‘never live without’.

Women in particular reported finding it easier to keep to a routine than men, regardless of whether they worked, retired or were stay-at-home parents. They described their various roles in their daily lives, and anchoring one activity to another to perform their assigned roles was a skill they learned along the way. For example, Naemah, a clerk, described the adaptive skills she used to ensure her daily inhaler therapy became part of her routine. She illustrated her description with a photograph (Figure 15) of her sweeping the house in the morning and made the following comment:
Figure 15 Sweeping the floor was Naemah’s daily chore.

Because, it’s not to say the house is dirty, [...], I just can’t hmm see the house in a mess, [...] especially if it’s dusty, that’s why before I go to work – I’ll sweep the floor. I’m working, a working mom – that’s a handful of things that need to be done. So, you see, my daily life is in order; one thing leads to the other. And it’s adjustable. Being organised and being adjustable is a skill-set (laughed); if you’re a multi-tasking mom, you would know. It’s a no-brainer. For example, I must make breakfast in the morning before I wake my kids from sleep, or else they have nothing to eat. Similarly, I have no problem using my inhaler daily. I just need to make sure I take it before I do something, like after I brush my teeth or before I shower in the morning. [Naemah, 38-year-old Malay woman]

Here, Naemah explains how she sees the incorporation of managing asthma as one of the many things she has to manage, and therefore, she expresses how her skill in multi-tasking is an essential transferrable skill to her overall management of living with asthma. By contrast, Teng recalled that his life had not changed much in the last 30 years, during which he went from factory worker to retiree.

I worked in that factory since I was 18. Before I retired, I was the supervisor of the production floor. I go to work and come home, eat and sleep. Nothing much changes; I can live without thinking (chuckled). Now, you asked me to use this (pointing to his inhaler) and do this and that. Change here and there. It’s confusing; there are too many things I need to do when they [the doctors] say I have asthma. I don’t know why I need to do this when I’m healthy [having no symptoms]. [Teng, 59-year-old Chinese man]

In this quotation, Teng compares his current, retired life and the challenges of incorporating his asthma self-care to his previous working life, saying that these appear to him to be very different. Teng further describes his lack of understanding of why he should take regular medication when he has no symptoms. When discussing how they adapted their lives to live with asthma, other men echoed similar challenges. However, a lack of understanding of
daily preventer use was a common finding reported among participants telling an endurance narrative, regardless of gender.

Identifying challenges – even if they were recurring, such as the occurrence of acute asthma exacerbations – and then overcoming them is a storyline that fits with the endurance narrative. Although some participants described being able to ‘accept life’ with asthma, they spoke of periods of frustration during acute ill-health episodes, especially when such episodes disrupted daily life activities, such as house chores. Their feelings of mastery of their asthma were aided by the activities they were able to engage in. Acute asthma exacerbations were found to temporarily impair these abilities and were reported to be a constant reminder of current limitations compared to one’s previous self. Participants sometimes recalled experiencing physical pain during these exacerbations and described how the recurrence of this pain prevented them from keeping up with their daily activities. Hannah, who is a stay-at-home mother, recalled her struggle with breathlessness and asthma’s physical pain, which disrupted her daily chores:

_Hannah, 59-year-old Chinese woman_

Living with asthma symptoms and having to rely on others to complete daily chores was described by many participants as frustrating. In the above extract,
Hannah expresses her sense of hopelessness during acute asthma exacerbations when she lost control of her daily routine. She links her shortness of breath to her debilitating physical pain and exhaustion. Being ‘sick’ and ‘unable to function daily’ was challenging for other study participants like Hannah, who echoed similar experiences. However, Hannah gradually came to accept her limitations due to her asthma, and she realised that when she was sick, she needed to take a break from her daily routines.

Living with asthma necessitates an adjustment in many aspects of life. Some participants reported being more alert to ‘the weather news’ to keep themselves abreast of environmental conditions, which triggered acute asthma exacerbations in some participants. Some opted for ‘less intense’ or less vigorous sporting activities to stay healthy and to prevent ‘exerting myself too much’. A woman who wanted ‘a big family’ reported having to ‘rethink’ these plans due to frequent exacerbations during pregnancy. The process of making these adjustments was not without challenges. Participants in this group described overcoming difficulties and persevering in the face of adversity by employing various coping strategies to live with the symptoms. Most participants in this study described their coping journey within a spiritual and/or religious frame of reference as a source for inner strength. Jesse, for example, committed herself to a spiritual journey to find peace. This is what she described:
It’s dark, but this is the Buddha statue at my house. Buddha himself teaches about peace and making peace with yourself and others. I believe him – I make peace with my problems and my health. I tried to forgive others who had wronged me. [...] I visited the temple very often, with [my] mum and sons. Just being there makes me happy and peaceful.

[Jesse, 37-year-old Indian woman]

She shared a photo (Figure 16) that she took of the Buddha statue to illustrate how she was coping with her life struggles. Jesse reflects on Buddha’s teaching about peace and making peace with worldly problems, such as health issues and relationships with others. She visits the temple as part of her life routine and coping alongside family members, reflecting support by family. Spirituality and religion are among the most widely described coping mechanisms used by participants on their journey to overcome their problems with asthma and acute asthma-related ill-health. Some participants gave other examples, including ‘meditation’ and ‘chanting of holy scriptures’ as the approaches they used to cope with the challenges of living with asthma. Others reported embracing ‘religious teachings’ and the ‘belief in the higher power’, such as the teachings of Islam, a religion embraced predominantly by those of Malay ethnicity, which is the largest ethnic group in Malaysia. For example, Yeop described an inner strength through religion.

During this conversation, Yeop shared a photograph (Figure 17) of a mosque and described it as a symbol of the faith he embraced. His complete devotion to a higher power gives him peace of mind and inner strength to face life’s adversities, both related to his asthma and life in general:
In summary, in the endurance narratives observed, the study participants described acceptance of living with asthma. In addition to this, they elaborated on how acceptance plays a crucial role in the construction of meaning in recovery from acute asthma exacerbations and saw acceptance of these experiences as a part of the chronic illness spectrum. For example, participants chose the therapies (e.g., complementary and alternative medicine or prescribed inhalers) for treating asthma symptoms that they thought worked and fitted best in their lives (e.g., according to their domestic roles). It was observed that responding to the challenges of living with asthma impacted both physical and mental well-being. However, participants overcame challenges and persevered in the face of adversity by employing various coping strategies to live with the symptoms (e.g., coping strategies within the spiritual or religious frame of reference).

- **Restitution narratives**

One of Frank’s proposed narrative archetypes is restitution [156]. The key elements of restitution narratives are the portrayal of illness as transitory, the natural desire to be well, and the association with the self ‘being’ a body rather than just having one. Frank describes this association as body-relatedness, referring to how a person relates themself to their body – do I have a body or am I a body? [156]. People may associate or dissociate themselves from their bodies. A person who desires to stay well often associates themself with
‘being’ a body, thus taking care of their body – the component identified in restitution narratives [156]. A fundamental backdrop of restitution narratives is the imagery of an ideal body over which one has complete control. Identifying this narrative is vital to illustrate how people with asthma and limited health literacy care for themselves, how their desires and sense of control affect them physically and emotionally, and how they cope with these effects.

In this study, restitution narratives were observed among some of the study participants. They retold stories about wanting to be healthy again after a period of acute ill-health. They used phrases like ‘good as new’ or ‘normal again’, which suggest a sense of control that allows them to resume their daily responsibilities or social roles once they are healthy. They were less likely to describe the physical burden of asthma but emotionally struggled to deal with the re-occurrence of asthma symptoms as they were losing control of a ‘healthy’ body. In the restitution narratives identified in this study, participants often reported a history of asthma ‘attacks’ that did not require emergency care or hospital admissions. Thus, their coping strategies revolved around controlling the acute symptoms, such as finding the right remedy for these symptoms and ensuring inhaler accessibility.

In reporting on restitution narratives, the restorable body concept [156] could mean two things: aspiration to be without asthma or respite from symptoms. The former concept tended to be described by most participants whose illness stories fell within the restitution narratives. For example, Kalsom, who worked as an office assistant, shared her narrative about her previous asthma symptom episodes. She explained

[...] When I was small, I did have asthma. But I got better when I was in primary school, I think when I was in Standard 5 [11 years old]. I was normal until I had the symptoms again now, but only when I was pregnant. If I’m not pregnant, I don’t have asthma.

[Kalsom, a 37-year-old Malay woman]

In the above extract, Kalsom describes her previous experience of asthma symptoms as a temporary acute ill-health state. The time when she was
symptom-free was perceived as a ‘normal’ or disease-free state, reflecting her desire to be free of asthma. Participants who shared similar illness experiences to Kalsom often described themselves as no longer affected by ill-health during symptom remission and as though their bodies were restored to their pre-exacerbation states.

In some cases, the aspiration to be without asthma led to the continuous search for external agencies to fulfil this aspiration. For example, Maryam, who is a stay-at-home mother, described her opinion about a cure for asthma:

*I know there will be a cure for my asthma. Any illness will indeed have a cure, right? Maybe for me, I have not found it yet. The inhalers, sometimes it helps, but sometimes not. That’s not good enough for me. I’m still sick. That’s why I tried the traditional and homemade remedies; anything you tell me that is good to cure my asthma, I’ll surely try it.* [Maryam, 41-year-old Malay woman]

This comment illustrates Maryam’s aspiration to be without asthma, which led her to experiment with a wide range of traditional and homemade herbal remedies. She perceived that her inhaler was ‘not good enough’ to help her achieve her goal, and this perception motivated her to keep searching for the right treatment for her. Across all ethnicities in this participant group, traditional and homemade herbal remedies are commonly ethnobotanical knowledge passed down from one generation to another. Many of the medicinal plants mentioned are homegrown, such as ginger or herbs used in Malaysian cooking. Letchumy, a 54-year-old Indian woman who shared a photograph (Figure 18) of black pepper and fenugreek, described these spices as ‘easy to find’, which was a reason to use these spices during an acute asthma exacerbation.

*Figure 18 Easy-to-find remedies for acute asthma exacerbations.*

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Maiza, on the other hand, evoked the restorable body concept as relating to her ability to achieve respite from symptoms. She commented about how the use of reliever and preventer inhalers restored her breathing and became part of her life. She not only carried her inhalers around in her handbag but kept another set beside her pillows, so she could reach these at night if she needed them.

From this experience, Maiza described photographing asthma inhalers next to her pillows (Figure 19) to demonstrate the significance of these therapies in controlling and alleviating acute asthma symptoms. Respite from asthma symptoms is critical for participants who are women, so they can fulfil their social roles (in this case, a mother caring for her children). She described her usual self as healthy and the inhaler’s role as keeping her breathing ‘normally’, reflecting the restorable body concept of ‘usual self’. This opinion was shared with others who had a similar opinion on the restorable body concept. It is common for this group of participants to feel secure knowing they have access to inhalers at all times. They may, for example, keep multiple inhalers around the house to ensure accessibility during acute asthma exacerbations.

**Figure 19 Inhalers under Maiza’s pillows.**

I’m not only carrying my inhalers in my handbag when I go out (chuckled). You see, my husband works in shifts, he’s rarely around. So, I’m playing safe [as] I have two children at home. I’m the sole caretaker, and I must be my usual self – you know, healthy. So, if I need to use the inhalers, I can reach for them. It rarely happened but I know if I need it, it’s at this place [under the pillow where I sleep at night]. If I can’t breathe, the inhalers can help me breathe normally, both, one after the other. I taught my kids that I keep the inhaler under here (the pillows; pointing at the photographs). My son knows what to do. He’ll just get me the inhalers under the pillow if I need it.

[Maiza, 31-year-old Malay woman]
None of the men in this study described experiences that could be identified as restitution. However, I noted from the analysis that the women of childbearing age (those aged less than 40) reported more eventful asthma episodes during their pregnancies. In addition, they reported experiencing more undesirable feelings, such as anger and confusion, when dealing with these episodes during their pregnancies than when they were not pregnant. Some participants attributed this emotional turmoil to the stress of bodily change, which impacted activities they enjoyed doing. Talking about this issue, Lin, who was 25 weeks pregnant, spoke about the frequency of asthma exacerbations during her current pregnancy:

*If I walk [excessively], my breathing [will be a] bit difficult. It's just that during this pregnancy [...] the breathing [difficulty] comes quite often [compared to] when I was not pregnant; I couldn’t do anything about it now. The breathing [will be] a bit difficult with this big belly, [I’m] snappy but have no idea why. I have to rest [a lot] more. I used to travel with my husband; we made travelling videos. Nothing fancy (chuckled) but we travelled to see places and try nice food, [but] now I cannot do [these]. My husband [has] no complaint but me, I feel, ‘haiya’ [a common expression to emphasise frustrations], I don’t know. [I’m] sort of angry, sad, frustrated all mixed up. I’m not like this usually, you know, too emotional. When I’m not pregnant, my breathing is normal, like last year only once [that] I needed to use the inhaler.*

[Lin, 22-year-old Chinese woman]

Lin reports that she rarely experienced any breathing difficulties when she was not pregnant, a common observation among other participants in this group when they spoke about their condition. She also shares that the exacerbations became more frequent and severe during her pregnancy, over which she had no control. Lin recalls how the increasing frequency of asthma exacerbations during her pregnancy impacted her emotional well-being. As a result of these exacerbations, she could not travel as she used to and missed doing so. However, some participants expressed concern that inhalers were ‘harmful
chemicals’ to an unborn child. Due to this concern, some believed in consuming and using only ‘natural products’ during pregnancy.

**In summary**, for the restitution narrative, the study participants described their definition of a restorable body (a bodily condition that is restored to pre-illness state and unchanged) in the aspect of aspiration to be without asthma and in the aspect of having respite from symptoms. Sense of control (e.g., placement of inhalers) and being able to resume social responsibilities (e.g., maternal roles) grounded these definitions and affected how they cared for themselves. In addition, it was established that acute asthma exacerbations were emotionally taxing, because the dread of losing control of one’s own body and life predominated (e.g., a pregnant woman’s emotional turmoil as her asthma condition worsened as the pregnancy progressed). Therefore, the reported coping strategies revolved around strategies to control acute symptoms (e.g., experimenting with complementary and alternative medicines).

- **Chaos narratives**

The third narrative type proposed by Frank identified in the analysis is the chaos narrative [156]. The anti-narrative of time without sequence is a key feature of chaos narratives [156]. In other words, the stories being told have no apparent cause or purpose and are not connected through time. In chaos narratives, all life events are contingent and unpredictable, and no one is in charge [156]. According to Frank, a body in the chaos narrative feels trapped by the demands of the moment and cannot reflect on these experiences [156]. A never-ending misery is frequently the backdrop of chaos narratives [156]. This type of narrative was previously used to describe life with chronic obstructive pulmonary disease (COPD) and medically unexplained symptoms [196,197].

Chaos narratives identified in participant interviews were without a plot or sequence. Living amid chaos, participants described being caught up in the misery of dealing with unpredictable and frequent asthma exacerbations. Identifying chaos narrative is empirical to understanding how the persistent ill-
health impacts their lives, physically and mentally. The chaotic experience of living with persistent asthma symptoms can be attributed to one of two scenarios. The first scenario involves participants who may have been diagnosed with asthma, but whose persistent symptoms may suggest an alternative diagnosis. The factors that could support such an observation about an alternate diagnosis were a reported history of smoking, occupational hazards, and co-morbidity. The story of chaos in people living with asthma may potentially raise the alarm of a misdiagnosis [197] or sub-optimal therapeutic management. Determining the presence of this condition is critical, and a tailored treatment strategy could be implemented to optimise the outcome. The second scenario involves people who have frequent severe exacerbations despite receiving optimal therapy.

For the first scenario, Amin’s life story is an example of what might seem to be an asthma-COPD overlap. He reported two risk factors to suggest this diagnosis: occupational risk and smoking. Amin is a 66-year-old Malay man who worked as a porter for 30 years. He smoked about 20 cigarettes a day for almost 30 years (a 30 pack-year exposure). Amin recalled his 30 years of work experience as a porter:

*I started to have asthma when I was about ten years [old]; it was not too bad, initially. Then, in the 1960s, I started working at the port. Everyone smoked, so did I. It was hard work, day in and day out. I needed to de-stress myself and hang out with my colleagues.

But not at the port – no, it’s too dangerous. There was lots of chemical substance there, with toxic substances and different kinds of gases. Many things (sighed). It was bearable during that time. [...] And then, the coal – we manually loaded it into barrels before they were carried into the ships. Malaysia exports a lot of sugar from the port. I worked at one of the sugar warehouses where we stored all these sugar sacks. It was misty, especially when we started to move these sacks of sugar. It looked like it was snowing (chuckled), I had never seen snow all my life, but I think it might be like that. It was the sugar dust. I worked for 20 years. Back then, I didn’t wear any masks. [...] I couldn’t recall when it started, this cough. But it seemed like the cough I used to have when I was small. But this time around, it stuck with me all the time.*
Sometimes my inhaler works, sometimes it does not. I was in and out of the hospital. There were a few times the ambulance had to come by at the port to take me. I just collapsed at work. [Amin, 66-year-old Malay man]

According to Amin in this extract, smoking was a stress reliever and a social norm among his co-workers. In addition to smoking, the working conditions he describes had significant occupational hazards for his lung health. This exposure led to the persistence of the cough he had had intermittently since childhood. Amin explains that he did not feel adequately protected at work, for instance, by using a mask. In addition, he describes how he was exposed to various substances, including toxic chemicals, over a long period of time. Given the environmental conditions of Amin’s work, he may be predisposed to diseases such as COPD or occupational lung disease. Misdiagnosis can result in inaccurate treatment and poor health outcomes [198], explaining Amin’s accounts of episodes of severe exacerbations he experienced.

Guna, on the other hand, reported experiences that could worsen his current chronic condition, which were thought to be asthma exacerbations. Guna was diagnosed with asthma, hypertension, diabetes and dyslipidaemia by his physician and is currently on multiple medications. He recalled his childhood before being diagnosed with asthma and how chaotic his life had become due to the unpredictability of acute asthma exacerbations, especially in the six months before the interview. Similarly, many of those with a chaotic illness experience often described their symptoms as unpredictable using descriptions such as ‘not knowing when it will come’ or ‘it appeared suddenly’. When asked about what hope he had, Guna took a long pause, and with a big sigh, replied,

*I don’t have any hope. No hope at all (sighed). I cannot eat many things – because I don’t know what will happen next. [If] I eat something wrong, I become breathless. I cannot sleep. I want to sleep because my body is too tired, right, but that also I cannot [do]. There were times when I fell asleep, but this (pointing to chest) would start making noises ‘boing’, ‘boing’. When that noise happened, I felt breathless. I couldn’t sleep. It has been two days...*
that I have not slept properly. I couldn’t sleep at all. I didn’t know what else to do. These are basic things in life – sleep, eat, breathe. If I cannot do these, what is the point of living? [Guna, 48-year-old Indian man]

As Guna’s description explains, the unpredictable symptoms deprived him of his basic needs, such as sleeping, which exacerbated his misery. He describes the feeling of losing control of his life due to debilitating symptoms and has very little or no hope in life. After an initial interview, Guna planned to participate in the photo-taking activity but was hospitalised before it took place. Guna’s wife contacted me to return his disposable camera, and I was informed that Guna had had difficulty breathing, requiring immediate medical care. Upon admission, he was described as undergoing emergency dialysis, which suggests acute kidney failure. Making consistent decisions about one’s health and navigating life around it is a constant struggle for anyone. In the case of Guna, the presence of multi-morbidities exacerbated this struggle, making it potentially overwhelming and challenging to manage.

The second scenario involves people who have frequent severe exacerbations despite receiving optimal therapy. This is exemplified through the stories of Nina, Lekha and Kiyya. Living with asthma symptoms was described as limiting their ability to live in the way they wanted, primarily affecting their social lives and interaction with others. Participants specifically recalled how persistent symptoms such as feeling breathless prevented them from creating social connections or making friends. For example, Nina, a technician, related an embarrassing experience of being breathless while talking to her friends. She explained

I feel limited in everything I do. [I] want to talk to people, [make] jokes and all that. Once, in the middle of the conversation, when everyone was happily chatting away, suddenly like [I] had to... had to stop what I was about to say, or excused myself, because I was feeling breathless. It wasn’t very pleasant. One time, as I was laughing at something my friends said, I suddenly felt breathless. All these interrupted conversations, [it was] not fun at all. Because everyone paused and turned to me when I became breathless, some
might start to panic, and the mood suddenly changes. It made me uncomfortable among friends. This asthma (sighed). ‘Why do I get asthma?’ I feel like that. [...] I hated these unwanted attentions. [Nina, 39-year-old Malay woman]

Nina’s frustrated tone was evident throughout her description of how asthma symptoms affected her life, especially in the above quotation, where she talks about feeling as though she is missing out and the enjoyment of spending time with friends being taken away. As a result, she could not keep up with their social activities and felt alienated from her friends’ company. She used many words describing her frustrations, such as ‘limited’, ‘angry’ and ‘embarrassed’. Nina blamed her asthma for preventing her from participating in the social activities she desired, and she despised the unwanted attention she received during an exacerbation. Similar experiences to those of Nina are echoed in the stories of other participants. They described avoiding social activities for fear of being judged and as a strategy to avoid stigma. Lekha, a part-time shopkeeper, gave an example of this:

*I don’t have many friends. I started not to be with my friends or go to their parties when my asthma [attacks] became too often. Back then, when I was in the company of others, I tried to avoid any question about asthma or went somewhere else if I needed to use the inhaler. After a while, I realised I couldn’t get on really well with people or make new friends because I tend to avoid them. So, now my world is just my family. I already lost contact with the friends I had before and I didn’t make any new ones. [Lekha, 31-year-old Indian woman]*

Lekha recalls avoiding being in the company of others to avoid being asked questions about asthma and being made to feel different. She reports that, over time, it became challenging to connect with others because of how she avoided their company, and she consequently lost meaningful relationships in the process. With a dwindling social network, participants with similar experiences to Lekha’s remarked on realising that they lacked trusting relationships where they could open up or share problems. Loneliness, life frustration, and frequent shortness of breath have frequently led to lingering thoughts of death, particularly after what they described as ‘near-death asthma
attacks’. Participants often felt that these chaotic experiences were beyond words. Describing such an experience, Kiyya recalled

_The [asthma] attack, I feel like I’m drowning and the pain when I can’t breathe. I can’t really describe this. It’s like I’m about to die, but I didn’t. And [I] experienced this over and over again. It’s like [a] mental torture (sighed). [Kiyya, 30-year-old Indian woman]_

This quotation succinctly expressed the traumatic ordeal of Kiyya’s severe exacerbations and how fundamentally she was affected by it. Other participants who had experienced similar breathlessness episodes often described their asthma symptoms as a feeling of being ‘suffocated’, a drowning-like experience, and ‘pain’. Kiyya took part in the photo-taking activity, and when asked what she could not photograph, she described a suffering soul and anxiety. She said

_I can’t take a picture of my suffering soul. Every day when I want to fall asleep, I will cry. I’m scared sometimes because I don’t know until when will I live. I am stressed. I’m not sure if I’m depressed! [Kiyya, 30-year-old Indian woman]_

Kiyya explained that these sufferings had had a profound effect on her. She often felt anxious about the possibility of an acute asthma exacerbation. She recalled a hyperventilation episode during an outing and had to stop her car when she realised that she had not brought her inhaler with her. She described her fear of dying if she had an asthma exacerbation without an inhaler. Like those of others with similar experiences, her stories featured hopelessness: she could not live outside her day-to-day sufferings because she was mired in her asthma exacerbations. According to Kiyya, Lekha and Nina, their daily lives were pervaded by contingencies that frequently went awry, and they considered that their desire to devise another coping strategy was futile.

_In summary, the chaos narrative was described by study participants through descriptions of life experiences and events that were devoid of sequence or storyline (e.g., one acute event after another). In addition, participants recounted the agony of dealing with unpredictable and frequent asthma_
exacerbations which fundamentally affected them (e.g., lingering thoughts of death). The chaotic experience of living with persistent asthma symptoms was due to several reasons: for example, the diagnosis of COPD versus occupational asthma.

Overall, participants’ descriptions of their illness experiences fit into three categories: endurance, restitution and chaos. Identifying these narratives uncovered the visible difficulties of living with asthma as well as intangible aspects such as emotional difficulties. I elaborate on these aspects in the discussion section at the end of this chapter. Below, I describe the participants’ experiences with identity.

**Theme 2: Reclaiming identity in the network of everyday relationships**

Participants described attempts to define their identities within their daily relationships, in order to make sense of their roles as individuals living with a chronic disease and to have some control over some areas of their life. In particular, occupational identities, as well as those shaped by social expectations, were the most common roles described by participants within this study. In their descriptions of occupational identity, participants described negotiating a sense of responsibility or belonging. The central aspect of managing social expectations was fulfilling caregiving roles, especially for women. Participants faced numerous challenges in conforming to expected social roles, but failure to do so was described as isolating.

- **Negotiating occupational identities**

The primary theme identified in negotiating occupational identities among people who were involved in paid work was the need to perform a role: ‘I’m a responsible worker’. Most participants who worked for pay, regardless of gender or ethnicity, expressed a desire to portray themselves as worthy of payment. Men in the study tended to centre their stories on their ability to hold down a job, which was often linked to depictions of masculinity, although their occupational role was frequently hampered by illness. In fact, their descriptions of asthma control reflected a mismatch between what this meant to the
participants and what guidelines define. When men described their work history, they reported a steady work history, often at great length, the various roles they played and their contributions to the organisation where they worked, all of which were conveyed as a sign of self-value. However, they expressed concern about not being able to ‘measure up’ to others as a result of their asthma.

For example, Nasir, who has worked for a large corporation for the past ten years, conveyed how he had successfully climbed the corporate ladder to become an assistant manager. With numerous details and elaborations, he described the highly demanding environment of his workplace and the important role he played in the organisation decision-making cascade:

*I’m the assistant manager, and I’m responsible for a department [which is] crucial in the whole organisation: I report to a manager, and he to the higher up bosses (chuckled). The guys up there needed someone [...] people [who are] very capable down here. Because when we work, we work like crazy until late at night. Until morning, we have to stand by for phone calls because we take care of the regional office. We worked in multiple time zones. A lot of the decisions being made by the bosses really depend on the information that my team and I feed them. [...] And these are the work I’m paid for; I must and will do it to the best of my abilities.* [Nasir, 33-year-old Malay man]

However, despite his significant role and contributions, he expressed concern that having and managing asthma symptoms would impair his functionality and future career prospects:

*So, when I have an [asthma] attack, the doctors will give me an MC [medical certificate]. Sometimes when I was given an MC because of an attack, I am afraid they’ll always say I’m among the weak ones, ‘Oh he’s taking too many MCs’. I am scared, and I freaked out. It’s like a pressure that I need to be fit and strong and run around completing my job. You know, the guys will say, I’m not like others and always on MC. I mean, I could recognise the look from my boss when I told him I got an MC for the day. When the doctor gave me MC, I didn’t want it and then went back to the office. If my asthma starts acting up during a meeting, I’ll try to*
control my breathing, or I’ll excuse myself for a short while and take a puff in the hallway. I tried to be OK, and I tried not to make it a big deal. I need to show them [the bosses] that I’m manager material and can fulfil the responsibilities that come with it.

[Nasir, 33-year-old Malay man]

Nasir includes a story about his efforts to maintain a work ethic despite his asthma symptoms. Nasir’s health decisions appear to be motivated by his desire to project the image of a responsible worker – someone who delivers results and does not frequently miss work due to illness. Other participants echoed his elaborations in their interviews, apparently choosing to prioritise their work identity over everything else, including their health. Like Nasir, they tended to downplay or normalise their asthma exacerbations by describing themselves or their situation using expressions such as ‘I’m fine’ or ‘this is nothing’.

Participants also described the importance of their roles in the workplace, citing phrases such as ‘I belong here’. According to study participants’ descriptions, their experiences of poor asthma control led to sickness absences. Moreover, it was these absences, participants explained, which invited criticism from other people at work.

Participants’ sense of belonging in the workplace was described as being influenced by their relationships with their co-workers and/or superiors. While having colleagues (particularly superiors) who were understanding and accommodating about their asthma at work was reported by many participants as making their work–health balance ‘easier’, a few participants did not have this advantage in their workplace. One participant described painful and unpleasant experiences of workplace ostracism as a result of his ongoing health concerns. Guna, who has worked in a factory for nearly three decades, recalled verbal abuse and rejection by fellow workers and shared a story about one of his encounters:

‘Hey you, sick guy. What kind of man are you? You’d better not come to work, take OT [overtime] if you always take sick leave. We had to do your job. Just go back home.’
I had been here even before they were born, those people! I knew every screw of the machines here [...] [Do] you know how sad that is? I know how to feel sad, too (looking away at the window). He does not know how bad this asthma is. [If] I cannot control [...] Their words hurt deeply. [...] They make it like there’s no place for me in that factory [...] That’s why sometimes, I skipped seeing the doctor when they gave dates to see them [for an appointment for asthma review] because I had no more leave. [...] I’ll just see them when I go for the neb [nebuliser therapy]. [Guna, 48-year-old Indian man]

In this extract, Guna states that the treatment he received from his colleagues stemmed from some of them being dissatisfied with having to cover for him while he was on medical absence. He justifies his belonging as a worker within the factory by citing his extensive time served and knowledge of the factory where he has been working. In this example, it is clear that workplace ostracism because of his ill-health had a negative impact on Guna’s sense of belonging. The stress appeared to directly affect his health-seeking behaviour, further contributing to, and possibly exacerbating, Guna’s existing problems of uncontrolled asthma.

- **Managing social expectations**

Some participants with children defined their parental caregiving roles in terms of providing physical and emotional security as well as ‘putting food on the table’. Men, in particular, evoked the good fathers they wanted to be through heroic portrayals of fathers who successfully provided for their families despite health challenges. In one case, as the primary breadwinner, Teng, who is a father of four children, reminisced about this role when his children were growing up. He described how he used to work at a flour packaging factory and was paid daily wages. He reported being diagnosed with asthma during his time working at the factory. At the time, he explained how he was prescribed two inhalers, ‘the brown and the blue one’ but only used the ‘blue’ inhaler (reliever inhaler), as he reported not experiencing any effect with the ‘brown’ inhaler. When asked if he took leave after an asthma exacerbation, he replied
As he explains, working with flour posed a challenge to Teng as it triggered frequent exacerbations, his (presumably) occupational asthma being caused by an immune reaction to agents that are inhaled at the workplace. His lack of knowledge around the preventive function of inhaled steroids (preventer) and over-reliance on the inhaled salbutamol (reliever) resulted in frequent exacerbations in the presence of the known trigger. Despite the difficulties, he describes how he persevered through these conditions to provide financial security for his family by persuading himself that he could overcome the obstacles.

In this study, women frequently reported having to juggle multiple gendered roles that defined their identities. The three commonly described roles were:

i) I'm a considerate wife;
ii) I'm a good mother; and
iii) I'm an obedient daughter-in-law.

In the role of ‘I'm a considerate wife’, affected women were concerned about being labelled. Labelling (e.g., as ‘ungrateful’) arose if they were found to discuss with others how their health problems interfered with their ability to run the household. This concern was due to their perception that their husbands took on the more ‘difficult role’ of ensuring the family’s financial security. There was a common understanding among women in this study who did not work outside the home that their role in household management was inferior to that of their career-oriented partners. As a result, these women considered that ‘discussing their health’ with their husbands was adding to the ‘burden’ that their husbands already faced at work. Despite the struggles that women had
with their health, particularly their ‘unpredictable symptoms’, these participants perceived the need to be a ‘considerate’ wife and ‘just get on with life’ rather than ‘complaining too much’. Some were even told not to complain. Illustrating this, Maryam gave an example of being told off, and how this impacted on her well-being:

> Sometimes, I couldn’t stand the [asthma] problem – the cough, the breathing. It kept coming. But I have to force myself to do work at home, tend to the children, [and] cook for my husband. My husband (sighed) once said, ‘you better just do your work at home, don’t complain too much. [You] keep saying you’re sick’, he said. From then on, I just tried to keep to myself, my problems. I don’t want [to] burden my husband. I think he had enough problems to deal with at work. I want to be a considerate wife (doleful expression) At night, I actually will feel sad, I feel useless because I don’t know how to tell him about my asthma […] about asthma, basically. I want to tell him, make him understand that I could die because of asthma, but why? How? When? These I don’t know!

[Maryam, 41-year-old Malay woman]

In this example, Maryam describes her struggles with frequent asthma exacerbations, which she has to deal with on her own in order to be a ‘considerate wife’ and avoid burdening her husband with her asthma. She describes having to force herself to continue with her life and duties, which she finds difficult in the absence of any support. As a consequence, Maryam describes feelings of helplessness and defeat – feelings shared by other women in this study who had similar experiences. Maryam’s inability to share information about asthma with her husband and to make him understand the consequences of asthma was a challenge that other women in this study faced.

Lack of support and acknowledgement from significant others about the challenges of living with asthma was identified as an important factor that affected several participants’ mental well-being and quality of life. One aspect of life reported by women in this study was intimate relations, including sex. For example, Jesse described challenges in negotiating with her husband regarding intimate relations and how she managed such situations. She stated
I don’t know how to tell him that I’m tired even to breathe with this asthma. What do I do? He wants to be together [sex], sometimes I too, but I might get breathless and need the inhaler. So, before we did it [sex], I drank warm water and rested for five minutes. [...] You know, people say this asthma is a cold illness, so you counter-act with hot kinds of stuff like warm water or ointment. Whichever option I can quickly get at home. [Jesse, 37-year-old Indian woman]

Jesse describes her inability to balance her struggle with breathlessness with the demands of an intimate relationship due to a lack of skills and knowledge. Here, Jesse’s health beliefs can be seen to influence how she manages her symptoms of asthma, and the therapy she chooses is determined by the options available to her.

In the ‘I’m a good mother’ role among study participants, maternal struggles with asthma symptoms were often related to a lack of awareness and knowledge about managing asthma symptoms triggered by physical activities. Some had to ‘limit’ their participation in indoor activities, while others described avoiding physical activities outside the home with their children due to previous exacerbations during such activities. Avoidance was identified as impacting on their quality of life and relationships among the family members, particularly their children.

Illustrating this case, Maiza, a mother of two children, used a photograph (Figure 20) to share her dilemma in negotiating a favourite family outdoor activity (going to the beach). She explained
Figure 20 Going to the beach with family could be a challenge for Maiza.

As a family, we always go swimming at sea; this is their favourite activity. But not me. I frequently make excuses not to go or suggest other activities. Sometimes, the children were quite upset with me, so I gave in. I want to be a good mother to them, you know, fulfil their wishes. But I know if I run or try to swim, my asthma [attack] will come. Also, I am scared of the water. [...]. Because I have asthma, I have this phobia, and I am scared that I will drown in the water because I know how it feels to ‘drown’.

[Maiza, 31-year-old Malay woman]

In this quotation, Maiza uses the example of a family activity that she avoids because of previous asthma exacerbations during trips to the beach and her fear of ‘drowning’, which she associates with her asthma symptoms. The decision conflicts with her wanting to be or to portray the image of a good mother and appears to impact on her relationship with her children.

The role ‘I'm an obedient daughter-in-law’ often relates to the concept of filial piety. Adult children caring for aged parents at home are aligned with the concept of filial-piety values, a social norm widely accepted in Malaysia. Filial piety is a Confucian concept adapted to religious teachings and cultural values in many Asian societies [199,200]. To be filial to one’s parents is to be responsible and to dedicate energy, disregarding one’s own personal comfort and convenience to care for the parents’ provision, nourishment, welfare and activities of daily living; and to make the parents happy through endowment and sustenance [199,200]. It can be a daunting expectation for someone who struggles with asthma to fulfil such a caregiving role, especially in an ‘in-law relationship’. For example, recalling her in-laws’ disapproval of her marriage because of her asthma status, Lekha explained how she felt about caring for her in-laws:
When I was about to get married, I had some problems because my husband’s mom said people with asthma, she said, ‘it’s a disease, don’t marry her. Later your kids will also get it.’ [At] that time I felt sad, but we got married anyway. [I] moved in with the family, and they expected me to be the daughter-in-law they could be proud of, an obedient daughter-in-law. You know, like a medal they could show around. After all that they put me through, they expect me to take care of them, do all the house chores for them, and I won’t complain about anything? [...] I’m just doing this for my husband. [Lekha, 31-year-old Indian woman]

The initial conflict appeared to affect the dynamic of the relationship between Lekha and her in-laws, and Lekha conveys that she cannot complain about how she is treated. The stigma of being a woman with asthma was shared by many women in this study, particularly those of Indian ethnicity, and was based on concerns that a woman might not be able to function ‘efficiently’ as a caregiver in multi-generational households, that she might be a ‘burden to the family’, or that she might ‘pass the asthma down’ to her children. Some of the participants in this study who cared for their in-laws said it was difficult to strike a balance between the demands of being an exemplary daughter-in-law and caring for their own health.

**In summary**, the two main issues with identity described by study participants concerned occupational identities, particularly among men in the workplace, and conforming to the domestic identities prescribed by society, particularly among women. Below, I discuss how people living with asthma and limited health literacy expressed their need to define the interactions they had with the health service and how they were unable to mitigate the challenges the environment posed for their asthma care.

**Theme 3: Defining interactions with the system and environment**

In addition to navigating identities and social roles, participants appeared to seek autonomy by redefining their interactions with the healthcare system and, to a lesser extent, with the environment. People bargained over their need to interact with the healthcare system based on their views about their need and their choices for the best asthma therapy to control symptoms. People with
multiple health conditions perceived asthma as unimportant, emulating how healthcare professionals managed and prioritised other medical conditions during the participants’ medical follow-up consultations or reviews. Managing environmental issues, whether indoor or outdoor pollution, was a significant challenge often necessitating lifestyle adaptations.

- **Previous experiences with medical care influenced engagement**

One example of engagement with the health system commonly described by participants was the regular follow-up consultations. Most participants attended follow-up consultations with healthcare professionals solely to ensure a constant supply of inhalers (particularly the reliever) via a doctor’s prescription and decided to skip reviews if they had sufficient supply. Attendance at the primary care clinic only costs MYR 1 (GBP 0.18) co-payment, which covers all the health costs, including the medications (See Section 6.3.2: Table 16). Reflecting on easy access to inhalers and the cost of medications outside the public health system, Teng described his perception about regular follow-up and how he made his decisions around attending a review:

> Ah, I don’t think seeing the doctor so frequently is necessary. If they give the appointment and my inhaler is finishing, I will come. If the medication [canister] is empty, the blue and the brown ones, I need more to control my asthma [symptoms]. Before this, when I was still working, if I missed the appointment. Never mind. I would go to the private pharmacy to buy lah [a common expression to emphasise strong opinion]. But now, I’ve retired already; I can’t afford to waste money like that. But if I have enough [in my inhaler], [there is] no need to go. Next time [when the inhaler] is nearly finished, I can just go to the clinic and bring the empty inhaler, exchange it for a new one, and set a new appointment date. But I cannot do this all the time, or I fear I will get caught [for] not coming to my appointment. The bottom line is, there is no need to see the doctor so often; as long as I have the inhaler, I can control my symptoms. [Teng, 59-year-old Chinese man]

According to this extract, Teng is managing his inhaler use in the context of limited funds and being economical with its use, but he is balancing this with
how he feels he is being perceived within the clinic. Teng believes he can simply go to the clinic whenever he needs a new inhaler, but he is influenced by his perception of how the clinic will judge his approach to managing his asthma, according to their own parameters. Yeop, on the other hand, shopped for the ‘original’ inhaler which, he reported, worked for him. He explained this by showing a photograph (Figure 21) of the inhaler which was prescribed for him and the one he bought:

**Figure 21 Yeop comparing inhalers.**

![Yeop comparing inhalers.](image)

_The clinic which I often go to has changed the type of inhaler in the clinic. So, the doctor gave me the new pump [inhaler on the left], it’s free, but [it] didn’t work for me. So, I buy another, just like my old pump [inhaler on the right] from the other clinic. This is the original and a better inhaler, they [the internet] said._

[Yeop, 28-year-old Malay man]

Here, Yeop did not trust the version of the reliever inhaler that his clinic provided, so he sought information online to challenge the new prescription. Yeop was not only taking his medications but he was actively seeking out the form of medication that he felt worked best for him.

Both Teng and Yeop took their medications regularly but had a different relationship with their medications and with the clinic that treated them. These two examples highlight how people’s engagement with the health system differed based on the cost of medication, and how they are interpreting compliance that does not always match up with what the clinic might expect.

Some participants described their understanding of the purpose of regular follow-ups by healthcare professionals. Participants referred to purposes including reviewing their asthma symptoms, checking their knowledge, reinforcing asthma education, and ensuring medication adherence. These participants felt that, with regular follow-ups, asthma could be well managed. Omar, who has good asthma control, gave an example of this:
For me, my asthma control is OK; everything is under control. I followed the doctor’s instructions and went and saw them on the appointment date. I follow how many doses I need to take, which inhaler I need to use. Now and then, the doctor will tell me this inhaler only can help control my asthma [symptoms]; if I skip it, I may get an attack. They tell again the things I may have forgotten, like [for example] to wear a mask during the haze. For now, my asthma is good

[Omar, 56-year-old Malay man]

Here, Omar reports that his asthma control is ‘OK’ based on self-assessment of his symptoms. He emphasises that following the treatment and advice from his healthcare professionals has contributed to the success of controlling his symptoms. It is important to note that Omar was one of only three participants in this study who had good asthma control; thus, these views about following treatment and asthma management were only identified in a minority of interviews.

There appeared to be a common understanding among the participants that the most important engagement with the health system is with the emergency services. Participants reported that if a reliever inhaler no longer controlled their symptoms, they would visit ‘the emergency’ (a common expression for the emergency department) as these services were easily accessible, particularly in an acute attack. In general, healthcare professionals do not advocate using nebuliser therapy at home to treat asthma [22], though several of our participants described having nebulisers at home in an attempt to make emergency management more accessible. There was a common perception shared by participants across this study that nebulisation was the ‘best step’ to control an attack. Illustrating this case, Nasir stated

If I need to get the neb [nebuliser therapy], I’ll go to the emergency [department], and my symptoms cease. [This is] good enough for me; the neb [nebuliser therapy] could help with my asthma. For me, I prefer to get the nebulisation when I need it. It is a go-to option [if] my inhaler doesn’t work. I don’t think I need to see the doctor when I’m well, like the follow-ups (chuckled).

[Nasir, 33-year-old Malay man]
Nasir explains in the quotation above that whether or not he seeks medical help is determined by the severity of his symptoms. He believes he does not need to see any healthcare professionals while in remission. The control concept in Teng and Nasir’s cases was based on their ability to control acute asthma symptoms, indicating a mismatch in understanding asthma and its control.

- **Making decisions on therapies that were perceived as being the best**

Participants reported that engagement with the health service was shaped by their previous experience of ‘successful’ treatment and their reliance on the medications that provided this success.

Some participants agreed that using an ICS or preventer inhaler during an acute attack effectively prevented an acute asthma attack. Based on their previous experiences, a proportion of the participants reported that oral steroids and oral salbutamol were equally effective (though over different timescales) in managing their acute attacks. Maryam described an example of this:

> When I had the attack, I sometimes took the white pills (pointing to a prednisolone image), around 3–4 tablets, and it would relieve the breathlessness. I would be OK, although a bit later. [...] From my experience, I can almost be sure I’ll be OK that day. No more attack that day or night. So, I won’t retake this after I feel OK. Just when I need it during the attack and to make sure my symptoms will not get worse.

> If I used the inhaler, my cough stopped very fast, but there’s a high chance [the asthma symptoms] will come again.

[Maryam, 41-year-old Malay woman]

According to this account, Maryam’s decision to take a single oral steroid dosage during an attack was informed by her previous observations of her condition after an attack. Although it took a little longer for her to feel better after taking the oral steroid, she noticed that her asthma symptoms would subside and would be less likely to reappear, at least for the day. This
perception was also reported by other participants in the study who used an oral steroid to treat an attack.

Although, officially, oral prednisolone requires a prescription from a healthcare professional, participants related that it could be obtained without a prescription from outside the public health system. Many had also accumulated oral prednisolone prescriptions from multiple after-hours visits for asthma exacerbations. Salmah, when discussing this issue, recalled having an excess of oral steroids at home:

*Every time I went to the emergency [department], they would give [oral steroids]. Sometimes I needed the nebuliser 3–4 times a month. Sometimes it would be the same health centre, but sometimes I needed to go to the one closer to my son’s workplace. It was easier there because if anything happened, my son would be by my side. At the moment, I have a lot of stock at home because I don’t take all seven tablets every day for one week. Usually just 2–3 days only. When I’m OK, I’ll stop.* [Salmah, 53-year-old Malay woman]

In this quotation, Salmah describes her choice of medical facilities as being dependent on family logistics, hence the description of visits to various emergency services. This series of visits resulted in Salmah having ‘a stock’ of prednisolone. In addition, her reported decision not to complete the entire course of steroid prescribed to her added more prednisolone to her stock.

In contrast, four participants described the efficacy of oral salbutamol in controlling the symptoms compared to the inhaler and continued using this despite the side effects. An example of this was Lekha’s description of managing her asthma exacerbation. She stated

*During the emergency [situation], actually, I didn’t use the inhaler. I took the medication. I could get better quickly with the ‘Asmin’ medication [salbutamol tablet] 4 [m]g. After that, I might have a bit of shaking, my whole body, but if I had to choose between shaking and breathless, I would choose the former. It would be less suffering, I suppose.*

[Lekha, 31-year-old Indian woman]
Despite the side effects, Lekha continued to take oral salbutamol because it reduced her asthma symptoms. She explained that she had to choose between the symptoms and side effects and chose the one that caused her the least suffering. Another participant, Letchumy, a 54-year-old woman, took a photograph (Figure 22) of oral salbutamol and described this as ‘effective’ at reducing the symptoms and ‘easy to carry around’.

• **Negotiating co-morbidities**

Participants older than 45 described a struggle to achieve a balance of attention between asthma and other health problems, such as hypertension and diabetes. Many of the participants in this age group who had other co-morbidities perceived that asthma was usually neglected unless they were symptomatic. An example of this is Rosmah, who shared a typical encounter with a healthcare professional during a consultation:

> When I went to see my doctors, they only asked a bit more about my asthma, [and] listened to my chest when I got the asthma attacks. If I was healthy and not looking breathless, no doctors asked me [about asthma]. They didn’t ask if I often cough or use the medications correctly. They were more focused on the blood pressure or the sugar, which is good because these are my main problems. If the sugar is high, they talk about adjusting the insulin and ask me to see the dietitian to look at my diet. Then my blood pressure was checked a couple of times if it was high, and they gave me a pamphlet; it explained how to check my pressure at home. By then, I think they had already forgotten I have asthma also (chuckled). I met others who have asthma only in the waiting room. They have seen the pharmacist for the inhaler, and then they get all these diaries, [but] nothing for my asthma. Is it that asthma is not as dangerous as other ailments? [Rosmah, 67-year-old Malay woman]

Rosmah describes how her diabetes and hypertension were given the attention and care they required, while her asthma was overlooked. This
contrasted with the more proactive care provided to asthma patients who did not have other health issues. She felt that her asthma condition was ‘forgotten’ by her doctors because she did not present with any asthma symptoms when they met with her, which gave her the impression that asthma was not an important disease. Other participants echoed the perception of asthma’s insignificance, citing a lack of priority given to asthma in consultation as the source of this perception. When asked about their adherence to asthma preventive therapy in their daily lives and when they were asymptomatic, they reported frequently neglecting this because they assumed asthma was only about controlling acute problems.

- **Doctor–patient communication and relationship with health professionals**

Despite being informed by health professionals that they have asthma and are at high risk of acute illness, some participants reported a lack of discussion with their health providers about how asthma will affect them in the long run. They also described a lack of discussion about managing asthma daily and the resources available to them in these conversations. For example, Norley, a retired woman, reflected on her experience when she was first diagnosed with asthma nearly 30 years ago. She recalled

> No one explained anything when I was first diagnosed [with asthma]. I think [it is] important when you first have asthma, they [the doctors] tell you all about it. The doctor did say I would have [asthma] attacks now and again, but that’s about it […]. This asthma will change my life, so tell me this. Especially the part that asthma stays with me to the day I die (chuckled), I think that is important. Any help I can get from anywhere other than the hospital? […] And this pump (holding up the preventer inhaler) is suppressing all the attacks, I didn’t know about this at the start. These are essential things to have a conversation about and be reminded of when I see the doctor. Because I admit it, I get complacent and forget about everything when I’m well. But when the attack came out of the blue, I panicked. OK, what to do? What to do? I asked myself (chuckled). We humans tend to forget, right?

[Norley, 63-year-old Malay woman]
According to Norley (and echoed by other participants), a lack of in-depth discussion about asthma and its impact on her life at the time of diagnosis contributed to a lack of understanding about how to manage asthma in everyday life. Norley also mentioned the need for constant reminders about how to handle exacerbations.

Other participants reported a lack of empathy from their doctors during consultations or treatment. A participant who experienced a side effect from frequent nebulisation therapy was one such example. Rose, who had been living alone since her husband’s death 10 years ago, described how doctors ignored her pleas and complaints about side effects during an emergency care visit. She stated that

*When I’m tired when they have given me neb [nebuliser therapy] over and over again, my body shakes (acting out an excessive trembling motion). [The] chest, dub, dub (making a heart-pounding sound while placing the hand over the chest, demonstrating forward-backwards motions), very fast. Still, they [the doctors] wanted to give me another neb [nebuliser therapy]. I shook my head; that was the only thing I could do – to say no to more neb. They would give two to three times more, together with the injection. Sometimes, I said to the doctor enough already – if the symptoms didn’t resolve, I would come again to see the doctor. Some would give in, but most would say, if I didn’t do this [take the nebuliser therapy], I would become worse, that’s all. I didn’t know how to explain myself, and I came alone, so there was no one to help. They [the doctors] didn’t know how shaking and this (pointing to the heart implying pounding of the heart) feels like. I feel like exploding, but how do I say it? No one listens anyway, I had to follow it the way they wanted it. […] That’s why, if I’m not that bad, I won’t to the emergency [department]. [Rose, 61-year-old Malay woman]*

During this interview, Rose made a series of dramatic gestures to express and describe her experience. She recalled experiencing side-effects from the nebuliser treatment she received during an emergency care visit, but because she arrived alone, she found it difficult to express these side-effects to the doctors. Rose recalled indicating ‘no’ for more nebuliser therapy but was told
she needed it, without being given any other options or explanation about the situation. Other participants who shared similar experiences discussed their feelings of ‘not being heard’ or ‘understood’. Some people felt ignored, especially when discussing psycho-social issues like childcare struggles, domestic problems, and life stressors such as having ‘not enough money’ and feeling ‘loneliness’ from living alone. Some participants reported avoiding medical treatment if possible or managing their acute asthma symptoms at home because they felt ignored, misunderstood or unheard. Such decisions were identified as a factor in delaying seeking medical attention in the case of near-fatal exacerbations described by some of the participants.

- **The environmental challenge of managing one’s asthma**

  The interviews provided examples of how environmental factors affect self-management; participants were aware of the risks but unable to mitigate them adequately. Many participants described the environment as another important factor that triggered their asthma but over which they had little individual control. Klang is an industrialised city near one of Malaysia’s busiest ports, Port Klang. Participants across the study described how their homes were close to smoke-emitting factories or the port, limiting their outdoor activities. They explained that relocating was not an option because they lacked the financial means to do so, and some of them had been living in these family homes for generations. As one participant, Habibah, put it,

  > There are many factories here. Even without the haze, I could smell the smoky air. It can sometimes be suffocating. Especially when no rain for 2–3 days. I have to stay at home, cannot go anywhere. Even then, my asthma still comes. The house is not a zip-locked bag: no smoke can enter the house (chuckled). [...] We, my husband and I, bought this house when we were still working and paid off the bank loan. Now that we have retired, we don’t think we can start paying another loan from the bank (sighed).
  > [Habibah, 73-year-old Malay woman]

  Habibah describes the challenges she faces due to living in an industrialised area polluted by factory smoke, which limits her outdoor activities. Despite the
impact on her health, she states that she cannot find better housing due to financial constraints.

Klang is also on Malaysia’s west coast, making it one of the areas most affected by the haze caused by Sumatra’s almost annual forest fires. While the haze affects many people, study participants recalled its impact on their lives even when the pollution was not yet visible. Naemah, a participant, shared a photograph (Figure 23) of an obscured sun and related it to acute asthma symptoms she was experiencing:

**Figure 23 An example of the start of haze season.**

You won’t see much now, but I have started coughing when I go out to work, and my chest will feel tight. You can’t see the sun and usually, around this time of the year where there’s not much rain, it’s the haze season. Try to see the news; you will see forest fires are starting to make the headlines. The typical mask will not work, but I can’t afford the good ones, so I avoid going out as much as possible. The mask is not cheap. [Naemah, 38-year-old Malay woman]

In this discussion, Naemah describes the impact of haze on her asthma control even before it is evident to the naked eye. She describes the need for a better mask to protect herself but explains the financial implications of using a mask as a long-term solution. Another participant, Lock, who worked in a factory in Klang, used to receive N95 masks from charities. N95 is a type of respirator recommended for protecting the wearer from hazardous dust, smoke, and particles as small as 0.3µ in diameter [201]. However, such a mask is costly. Lock explained

I don’t know the name of the good [quality] mask, white in colour, a bit hard and rounded, like that (placing a dome-like hand over his nose and mouth). The charity said I shouldn’t wear the mask the doctor used, [as it is] unsuitable for the smoke. They gave the
good one, but when I try to see if this is sold at the pharmacy, ‘haiya’ [a common expression to emphasise frustrations], why cost so much? If haze a few months, cannot buy that many. [So], I recycled. [Lock, 78-year-old Chinese man]

Lock describes what appeared to be an N95 mask provided by a charity organisation that distributes the masks to the public. He states that he reused the mask as much as possible as he could not afford to replace it. When asked if he had any other plans to manage his asthma during the haze episodes, Lock said he was taking his medication as usual, despite experiencing more coughing or shortness of breath.

There were examples of difficulties in negotiating unhealthy practices in participants’ households that resulted in indoor air pollution, such as smoking. The majority of those who shared these stories were women whose husbands smoked in their homes. Despite having frequent asthma symptoms in the presence of their husbands, women in this group reported difficulty discussing their health concerns with their partners. Some women described how they felt that their partners did not understand the needs of people living with asthma. For example, Maryam illustrated her difficulties managing asthma at home by photographing tobacco products (Figure 24) that she accidentally discovered in her partner’s truck. She explained

**Figure 24 Home-made cigarettes.**

I don’t think he understands [...] My husband smokes, and it makes my asthma difficult to control. He makes his [own] cigarettes, with [...] the dried tobacco leaves, crushed cloves with the tobacco leaves, and rolls the paper. He made many cigarettes from one tobacco packet. [...] That’s why he can’t stop. [Maryam, 41-year-old Malay woman]
In this case, Maryam blamed her husband’s smoking habit for her asthma exacerbations. She said that the number of cigarettes her husband would make meant he was highly addicted, making it difficult for him to quit smoking. In addition, his continued behaviour was exacerbated by the fact that rolling his own cigarettes was significantly cheaper than purchasing regular cigarettes.

6.5 Discussion

6.5.1 Summary of findings

Three themes were identified in the narrative approach to analysis. The concept of autonomy was central to all themes: the participants expressed a desire to have the to control decision-making about their health. The themes identified in this analysis were as follows:

i) Asthma is a life story;

ii) Reclaiming identity in the network of everyday relationships; and

iii) Redefining interactions with the health system and environment.

Table 22 summarises the overall results. Living with asthma has been described as a life story about coping with the symptoms of the disease and the physical and emotional burdens the condition brings. Participants in the studies reported a loss of identity, particularly in the contexts of their occupations and meeting societal expectations. Participants reported being unable to deny the necessity of interacting with the health system as a person living with asthma, but their lack of knowledge about health posed a significant challenge in defining these interactions. Managing environmental challenges was an aspect that participants were aware of but lacked the means (skills, knowledge, and finances) to negotiate.

**Table 22 Summary of the overall results.**

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### Physical and emotional burdens of living with chronic symptoms

Participants described the burdens (physical and/or emotional) associated with living with asthma symptoms across all narrative types.

Participants whose experiences corresponded to the chaos narrative found it impossible to negotiate their way out of the difficulties they faced.

However, in other participant groups (endurance and restitution narratives), participants described how they coped with challenges and reported how they navigated around these challenges in their own unique ways (e.g., using spiritual or religious framework).

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### Coping mechanisms

**Reclaiming identity in network of everyday relationships**

Participants described attempts to define their identity within their daily relationships in order to make sense of their role as a person living with a chronic disease and to have some control over some areas of their life.

In particular, occupational identities, as well as those shaped by social expectations, were the most common roles described by participants within this study. In their description of occupational identity, participants described negotiating a sense of responsibility or belonging.

The central aspect of managing social expectations was fulfilling caregiving roles, especially for women. Participants faced numerous challenges in conforming to expected social roles, but the result of failure to do so was described as isolating.

**Negotiating occupational identities**

**Managing social expectations**

**Redefining interactions with the health system and environment**

Participants appeared to seek autonomy by redefining their interactions with the healthcare system and, to a lesser extent, with the environment.
| The environmental challenge of managing one's asthma. | Participants of this study bargained over their need to interact with the healthcare system based on their views about their need and their choices for the best asthma therapy to control symptoms.  
Those with multiple health conditions perceived asthma as unimportant, emulating the way healthcare professionals managed and prioritised other medical conditions during the participants' medical follow-up consultations or reviews.  
Managing environmental challenges, whether indoor or outdoor pollution, was a significant challenge often necessitating lifestyle adaptations. |

6.5.2 **Strengths and limitations**

**Recruitment**

The participants were recruited from multiple sites, representing the varied socio-demographic backgrounds of the Malaysian population. Recruitment was challenging, as the screening questionnaire for the HLS was long. This might have discouraged some people with limited health literacy from participating, since people with poor literacy skills will typically avoid situations requiring reading or form-filling. Thus, I assisted most participants in filling up the HLS questionnaire. Ideally, the screening questionnaire should be self-administered. Due to this assistance, social desirability and response bias might have affected the screening results (e.g., such biases might have led to an underestimation of the true limited level of health literacy; thus, these potential participants might have been excluded). Another limitation of the tool was that the HLS tool only assessed overall health literacy and did not reflect participants' specific asthma knowledge. However, understanding asthma was explored in the qualitative interviews, thus overcoming the need for a tool to assess knowledge about asthma. In screening participants with a health literacy questionnaire, I found that participants were not intimidated when
discussing the screening results. Most shared a common understanding that they did not know much about health. Some participants considered the result as of no surprise, as they believed only the doctors knew about asthma and about how to manage their condition appropriately.

**Ensuring accessibility to research for people with limited health literacy**

Patient information sheets are typically detailed, potentially complex, and run the risk of being off-putting to my target population (people with limited health literacy). Therefore, I prepared a participant information video to accompany the information sheet, to provide accessible information and improve understanding of what was involved in the research. The video-based information that supplemented the paper version was available in four languages. Furthermore, the use of infographics to explain the conduct of Photovoice encouraged participants to be creative in completing photo-taking tasks, embracing the different ways people may learn new knowledge. Finally, giving participants a choice of photographs to discuss in research interviews and engaging stakeholders in dialogue were strategies I used to instil empowerment, improve research experience and provide a platform for people to express their needs and challenges.

**Language**

Interviews were conducted in the participant’s spoken language to capture the cultural nuances, which I preserved during the translation process. Nevertheless, as the main and bilingual (Malay and English) interviewer, I required an interpreter when interviewing participants who preferred to speak in Tamil or Mandarin, and the use of an interpreter might have influenced those interviews. However, as an experienced member of a research group working in a multilingual society, I am used to working with interpreters. For example, to ensure equality in the power dynamic and communication flow between myself and TP, we would discuss our reservations and concerns about each interview, to avoid the feeling of one of us having more authority than the other. I worked with TP throughout the data collection timeline to ensure uniformity in the way the interviews were conducted and the conversations interpreted.
Data analysis was discussed with a multidisciplinary research team (including general practitioners and social scientists), which provided diverse insights into the interpretation of the study findings.

The use of visual materials proved an essential factor in overcoming linguistic challenges. For example, a participant who spoke a mixture of Tamil and Bahasa Malaysia languages wanted to express the lack of privacy in a clinical consultation room, but she struggled to describe this. She then drew a diagram, which I photographed, to aid storytelling. Thus, despite the language differences, I understood the story as it was told and appreciated the participant’s perceptions.

**Adaptations of Photovoice**

The initial in-depth interviews were representative of the intended range of demographic characteristics and asthma control, though only a minority of the participants took part in the Photovoice phase, in part because of the commitment of time and effort needed to complete this. Two participants who expressed interest in participating in Photovoice were hospitalised during the study period due to asthma and complications of multi-morbidities. Had they participated, they might have gone on to explore more issues, but the initial interviews gave an insight into their struggles. Older individuals interested in Photovoice found operating a disposable camera during the training challenging, notably winding the film after each take, owing to arthritis. Additionally, a population survey in Malaysia reported that in urban settings, those of Chinese ethnicity were more likely to access private health services [162]. As a result of these factors, fewer older participants and those of Chinese ethnicity completed the Photovoice activities. In classic Photovoice methodology, I would only have recruited participants willing to commit to the photo-taking. Instead, I adapted this approach by including initial qualitative interviews, which meant I heard from a broader range of people, enabling me to embed Photovoice insights in the broader context.
The strengths and limitations of using an adapted Photovoice methodology

Through using images, the photo-interviews became an extension of and added depth to the initial interviews. In all interviews, the presence (or absence) of the images allowed discussion of topics that mattered to the participants, such as relationships and norms. For example, from photographs of therapies used to treat asthma, I discovered that most participants used home remedies and complementary and alternative medicine to treat subjective experiences and feelings before actual asthma symptoms emerged. This discussion started when a participant arranged the photographs of therapy she used before and during an exacerbation. Another essential aspect of Photovoice, which may have helped enhance participants’ research experience, was discussing the image each participant could not photograph. This exercise challenged the way the participants thought, and the absence of these photographs helped people reflect on pertinent – but hidden – issues such as mental health. Another case was occasioned by the fact that taking photographs in a consultation setting is not the norm; thus, to visualise a crowded consultation room, a participant drew a crude example of the people she saw within a consultation she attended. Thus, the interviews and photographs provided a data source triangulation that enhanced and extended the understanding of health literacy experiences among people with asthma in Malaysia.

I did not explicitly uncover a new understanding of limited health literacy through the photographs. However, the photographs contributed to a better understanding of health literacy as a social practice: health-related decisions were not just made from evidence-based scientific knowledge but were influenced by health practices the society considered normal and effective. This understanding is essential in this multicultural and multilingual setting. Additionally, the recruitment timeline meant that initial interviews were concurrent with photo-interviews; thus, the findings of the two approaches could iteratively influence each other.
The ethics of camera technology and photographs themselves were the limitations. The camera technology in this study limited the quality of the photographs (Figure 25). The decision to use a disposable camera was made to ensure compliance with ethical requirements for maintaining the participants’ privacy and the safety of the photographs they had taken [202,203]. Digital photographs taken on a camera phone did not meet the stringent security requirements of data protection. The use of mobile phone cameras would have raised concerns regarding the researcher’s control over the data and the confidentiality of human subjects whose photographs have been taken under the pretext of research [202,204]. With digital technology, photographs taken for research may be copied or shared, resulting in issues about anonymity and confidentiality, especially if these photographs were identifiable [202,203,205]. For example, participants were trained to avoid taking identifiable pictures of people (even though the interviews suggested that family and colleagues were important to participants living with asthma). One participant brought several identifiable photographs, some of which were taken using mobile phone camera. I accepted all photographs, however they were taken, used them for analysis, as these photographs played essential roles in the interviews none of these photographs were reproduced as output of the research.

*Figure 25 Quality of photographs: limitation of the disposable camera.*
A positive benefit of using a disposable camera, which was highlighted during the photo-interview, was the careful thought participants put into selecting what to photograph. Unlike using a digital or mobile phone camera, participants could not see the quality of the photographs they had taken using a disposable camera, and the use of a film roll meant that there was a specific, finite number of photographs that could be taken.

6.5.3 Interpretation of results and comparison with the literature

What do illness narratives tell us about living with asthma?

The narrative analysis identified three types of narrative typologies that described participants’ experiences of living with asthma: endurance, restitution and chaos. This is not to say that this is the only way the narratives could be classified or that components from more than one type cannot coexist in the same story [156]. However, paying attention to illness narratives aids in mapping events such as the frequency of asthma exacerbations and service use, which may resonate with different illness trajectories and have clinical implications.

Participants whose illness narratives matched the endurance narrative were observed to have a clear sense of biographical disruption. The concept of biographical disruptions centres on how an individual experiences illness and re-adjusts their identity and biography due to their illness experiences [206]. These participants’ accounts indicated a life of perpetual adaptation and coping strategies in order to maintain their identities. As exemplified in my
findings, constantly adapting to life was a challenge to many. Continuous support, both social and psychological aspects, are vital to maintaining positive behaviour change regarding asthma and its management [5].

In the restitution narrative, participants in this study perceived asthma as an intermittent condition. The perception that asthma is an intermittent condition, rather than a long-term condition which requires long-term prevention, may lead to suboptimal asthma self-management [14]. Recognising restitution narratives among people with asthma may reflect the mismatch between patients’ common-sense interpretations of their condition, treatment and medical reasoning. The sense of control revolved around strategies used to control acute symptoms (e.g., widespread use of complementary and alternative medicine), reflecting the mismatch between what asthma control meant to the participants and what guidelines define. Such a difference of understanding is likely to affect health outcomes and long-term management. A mismatch in the definition of control between healthcare professionals and people with asthma is common in the literature [207]. This mismatch in the understanding of asthma control may challenge people’s ability to self-manage their asthma. Providing education and training about asthma and self-management in a way that supports understanding based on health literacy needs and involvement of key people in social networks (e.g., family members) [208-210] might improve understanding of asthma and its management.

In the context of the chaos narratives in this study, living with persistent asthma exacerbations was unpredictable and chaotic. People living in such chaos had no sense of biographical disruptions and suffered from loss of self over time. As described by participants in this study, they were fundamentally affected mentally due to chaotic illness experience and may have been less likely to seek out the help or support they needed. Thus, paying attention to, for example, those with uncontrolled asthma or those who frequently require emergency care and/or hospitalisations would likely identify at-risk people. If subject to early intervention, the people at risk of chaotic illness experiences were likely to benefit from early multidisciplinary and social support [197]. It
was thought that careful assessment of the need for supportive care should be triggered at key disease milestones, for example, after hospital admission for exacerbations [197]. Although the study by Pinnock et al. did not include people with asthma [197], it reflected the illness experiences of my qualitative study, especially people with multi-morbidity and potentially with asthma-overlap conditions.

**Personal autonomy versus relational autonomy**

People learn to live with asthma and establish particular preferences for health management. In an era of modern medicine that places a high value on evidence-based management, disruptive events of chronic illness (in this case, acute asthma exacerbations) are frequently managed in the way practitioners perceive best, leaving patients’ experiences and constructions of meaning at the margins of management. The deep participation of medicine in people’s illness experience inevitably involves control issues in health decision-making and management. My findings reflected participants’ desire to control many elements of their lives and make health decisions while perhaps being hampered by limited health literacy and the societal disadvantages that go with it. It is this personal autonomy that every healthcare professional must respect. Respect for autonomy revolved around confidentiality, privacy and truth-telling, and allowing patients to make autonomous decisions about their health [211]. The concept of respect for autonomy requires healthcare professionals to inform patients about their health and management alternatives; then step back, allowing them to make decisions and follow through on those decisions.

The findings of this study, however, revealed that participants sought advice from their families and made health-related decisions that were typically aligned with their cultural norms and practices. This process is described as relational autonomy [212]. Relational autonomy emphasises that people are constantly placed within interpersonal interactions and larger social settings, which are pervasively influential [212]. In this study, the emotional and physical burden of living with recurrent asthma symptoms altered self-identities and life goals. It required adjustments in connections and interactions with others, all
of which had an impact on autonomy and further diluted the control people had over themselves.

In terms of contacts with the health system, participants reported that prior contacts with medical services influenced future decisions to engage with clinical care. The participants’ accounts suggest that, in many of these exchanges, their autonomy had been undermined as a result of the patient–doctor interactions they had encountered. Although patients recognised that healthcare professionals knew considerably more about asthma and health than they did, they considered that they had something to contribute to management plans, and they wanted to be recognised for this contribution [59]. Clinical interactions should support people’s autonomy in coping with troubling symptoms, diagnoses or treatments by assisting them to form, maintain or re-establish self-identities with which they are comfortable, as well as supporting them in dealing with emotions and social stigma [212]. As described in this study, patients and their families’ health beliefs and culturally defined health practices dominated the conversations around asthma management. Healthcare professionals need to be aware and respectful of patients’ health management choices to deliver quality asthma care in multicultural settings [213]. Effective doctor–patient communication may lead to better understanding about health and its management and is likely to have a positive impact on health outcomes [57,58].

The intangible aspects of asthma and self-management

It is recognised that people with asthma have a different perspective of their disease compared to their healthcare professionals [214]. However, very little is known about how limited health literacy affects perceptions of asthma and its management. In addition, while literature describes the potential psychological impact of living with asthma (e.g., depression and anxiety), few studies describe the complexities of the emotional experiences and factors that affect psychological well-being. This study found that patients describing severe asthma exacerbations as an ordeal that fundamentally affected their
lives. Descriptors of the physical experience of asthma in this study respond to a review [171] which called for further objective exploration.

Anticipating judgement from others in one’s network of interpersonal connections and social milieu was a crucial feature of people’s illness experience. This study highlights how stigma, real or perceived, was a significant concern to many participants. People may cope with judgement, labelling and stigma differently: some might opt to conceal or selectively disclose their condition, downplaying their symptoms or taking proactive measures to maintain good asthma control (e.g., using peak flow to detect deterioration) [171]. Although asthma symptoms range from mild to severe, depending on age and person, knowing how people perceive their environment and respond to it is a first step in addressing and explaining how and why people with asthma and limited health literacy have diverse experiences of asthma. This understanding is important, as such perceptions could be a barrier to medication adherence and seeking medical help.

Everyday occupations and social roles were linked to the identities of the people in this study. Narrating everyday identities is a process through which people make sense of their lives and determine how they see themselves and others [215]. This process could assist people in managing, reorganising and focusing on essential life issues such as their asthma care. This study highlights the fact that many participants struggled to define themselves through everyday identities without the right support. Grounding themselves in practical everyday roles assisted people in discovering their identities and finding significance in everyday life, even when their performance abilities were hampered by asthma [216]. This is an essential insight, as adequate assistance may enable people with chronic illnesses to continue being part of the workforce and participating successfully in their social context.
6.6 Conclusion and implications for intervention development based on this qualitative study

In the narrative analysis of this qualitative study, I learned the following:

- Adaptations of the qualitative study methods were crucial to conform to local needs and be responsive to cultural sensitivities.
- Participants’ empowerment, and the collaboration between the researcher and participants, were enhanced through the innovative and creative research process.
- The concept of autonomy was the primary lens that participants used to describe their experiences living with asthma.
- The challenges they faced are multilevel; thus, intervention to improve people’s illness experiences requires a whole-system approach.

6.7 Summary and next step

This chapter described the adapted Photovoice methodology that I used in the qualitative component of my PhD. In this study, photographs taken by people with limited health literacy provided a creative space for them to narrate, through a non-verbal medium, their experiences of living with asthma. I adopted a narrative approach to analysis to explore experiences of living with asthma and identified key themes emerging from the stories people told. The overarching theme identified in this study was the search for autonomy. Through the narrative approach to analysis, I identified three themes that drove how participants searched for autonomy in their lives. The first theme was asthma as a life story. The illness narratives of living with asthma symptoms identified in this study were of three types: endurance, restitution and chaos. The second theme highlighted how people living with asthma strove to gain autonomy through reclaiming their identities within a network of everyday relationships. Among the identified identities were occupational identities and socially imposed identities. Finally, the third theme concerned how people with asthma and limited health literacy sought to redefine their interactions with the health system and, to a lesser extent, the environment to gain autonomy.
Participants' perceptions of their needs influenced their decisions to interact with the health system. I identified several barriers that had negative impacts on engagement. The environmental aspects were found to be challenging to manage.

In the next chapter, I report the results of the framework analysis that I conducted on the same data. Informed by Sørensen's health literacy framework [36], I examined the themes around how health literacy influenced the understanding of asthma and informed self-management decision-making. This analysis also identified the barriers to applying evidence-based self-management practices among people with limited health literacy and how these barriers can be overcome.
Chapter 7  Health literacy framework analysis.

In the previous chapter, I described the adaptation of an arts-based qualitative method, Photovoice, and the first part of the analysis, the narrative approach to analysis. This chapter explores the role of health literacy in understanding asthma and how it influences decisions about self-management, and it also identifies barriers to using evidence-based self-management plans among people with limited health literacy and discusses how the use of such plans can be supported. The analysis for this chapter uses health literacy framework analysis [217] as described by Sørensen et al. [36].

Figure 26 depicts the work I undertook for the entire PhD programme of work, which is reported in this thesis using the 6SQuID model (Steps 1 to 4) [107]. The red circle refers to the part of the work discussed in this chapter.

Figure 26 Using the 6SQuID model as an overall framework for this PhD.

7.1 Sørensen’s health literacy framework

Sørensen’s health literacy framework is described in Section 2.2.1. In summary, health literacy is related to literacy. It encompasses people’s knowledge, motivation and competencies to assess, understand, appraise and apply health information to make everyday decisions concerning healthcare,
disease prevention and health promotion to maintain or improve quality of life throughout the life course [36]. I used the same four domains of health literacy as Sørensen et al. to inform my analysis, and the definitions of these domains are as below [36]:

- **Access** refers to the ability to seek, find and obtain health information.
- **Understand** refers to the ability to apprehend the health information that is accessed.
- **Appraise** describes the ability to interpret, filter, judge and evaluate the health information that has been accessed.
- **Apply** refers to the ability to convey and use the information to decide on the maintenance and improvement of health.

I drew on Sørensen’s health literacy framework to understand how people with limited health literacy understand asthma and make self-management decisions, the barriers to using evidence-based self-management plans, and how the use of such plans can be supported. I later adapted Sørensen's health literacy conceptual model to be suitable for the health literacy framework that informed the prototype of my intervention development.

### 7.2 Objectives of the health literacy framework analysis

To explore experiences of living with asthma among people with limited health literacy in Malaysia:

a. to explore the role of health literacy in understanding asthma and how it influences self-management decisions, and

b. to identify barriers to using evidence-based self-management plans among people with limited health literacy and to identify how the use of such plans can be supported.

### 7.3 Methods related to the health literacy framework analysis

A framework analysis considers pre-identified issues that the researcher has planned to explore while also allowing for flexibility for new themes [217]. The health literacy framework was useful to investigate whether participants had
developed skills aligned with the domains of the health literacy framework and to discover new ways in which the framework translates in real life.

To answer the objectives, I drew on the framework approach to analysis as described by Gale et al. [217], which involves seven stages:

i) transcription,
ii) familiarisation with the interview,
iii) coding,
iv) developing a working analytical framework,
v) applying the analytical framework,
vi) charting data into the framework matrix, and
vii) interpreting the data.

The transcription process, including the translation, was described in the previous chapter (Section 6.2.4). The transcripts were read and re-read to check the accuracy of the transcription process and the translations. To ensure familiarisation with the interviews, I listened to the audio recordings several times: after an interview (to gain a general sense of the data), as well as before and after the recordings were transcribed. All the transcripts from the initial in-depth interviews and photo-interviews were uploaded into the qualitative analysis software (NVivo 11). I deductively coded the transcripts using the domains of Sørensen’s health literacy framework concerning the use of asthma related-health information: access, understand, appraise and apply [190]. I created separate codes for each of the four domains. Each transcript was read, and each interview statement was coded into one of the health literacy domains. These domains were further divided into ‘conforming’ and ‘non-conforming’ themes to the domain. See Appendix 20 for working examples of the health literacy framework analysis.

7.4 Results of the health literacy framework analysis

7.4.1 Summary of participants’ characteristics

These are the same 26 participants and the same interviews as described in the previous chapter (Section 6.3.1).
7.4.2 Presentations of findings from the health literacy framework analysis

The key theme in this analysis is that people living with asthma negotiated health information provided by the health system with reference to their social norms and culturally determined health practices. The findings were constructed within the four domains of Sørensen’s health literacy framework: i) **Access**; ii) **Understand**; iii) **Appraise**; and iv) **Apply**, in the context of health information. I explicitly looked for discordant views and unexpected themes, to ensure all views were included. Table 23 provides a summary of the overarching theme.

**Table 23 Summary of the overarching theme of health literacy: negotiating medical narratives and social practice.**

<table>
<thead>
<tr>
<th>Domain of health literacy</th>
<th>Sub-themes</th>
<th>Examples</th>
</tr>
</thead>
</table>
| **Access** to information on asthma and self-management | Formal and informal sources of health information | • Healthcare professionals as the primary source of knowledge on asthma  
• Health pamphlets and talks improve asthma knowledge  
• Family members contribute to asthma knowledge  
• Social media provides experiences of others |
| **Understanding** information on asthma and self-management | Understanding of asthma based on basic scientific understanding | • Chronic illness may be related to other inflammatory diseases  
• Illness may vary over time and depending on intensity and health state (e.g., pregnancy)  
• Medications can only control asthma symptoms  
• Triggers can be internal and external factors |
| **Health beliefs may shape understanding of asthma and perceptions of control** | • The belief that coughing is an infectious disease related to tuberculosis  
• Health beliefs are anchored to religious belief and identity |
| **Factors affecting understanding** | • The use of the national language on health information limits the understanding of those who speak only or mainly their native language  
Communication skills – verbal and non-verbal – of doctors affect understanding |
| **Appraisal of information on asthma and self-management** | **Lack of appraisal strategies**  
• ‘Just follow’ |
| **Experiential knowledge aids in evaluating the information on asthma** | **Comparing information with own experience** |
| **Application of information on asthma and self-management practices** | **Established self-management practices were a mixture of science-based knowledge, social norms and culturally determined health practices**  
• Social norms and culturally determined health practices influenced the self-management decision-making process  
• Widespread use of home remedies or alternative therapies as first-line or concurrent use with inhaler therapy  
• Widespread over-use of salbutamol inhalers during attacks  
• Self-prescribing using systemic steroid or salbutamol tablets due to the perception that these treatments are effective  
• The belief that nebulisation is better than inhaler therapy, and consequent misuse of emergency services |
| Challenges in using guideline-recommended self-management | • Stigmatising experiences influence self-management decisions  
• Lack of awareness about evidence-based self-management practices  
• Challenges in using written asthma action plans (e.g., they are perceived as too wordy)  
• Those who have seen the plan perceived it as useful knowledge, although understanding and application require continuous support from healthcare professionals, family and technology  
• Multilevel recommendations made to improved uptake and use of guideline-recommended care |

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Access to information on asthma and self-management

Participants described two sources of information about asthma and self-management practices. The primary formal source of information was healthcare professionals. Participants considered it the doctors' duty to share information about asthma, its treatment and how to care for it at home. Doctors were perceived as health experts and trustworthy sources of information. Reliance on the advice of healthcare professionals also overcame the participants' lack of confidence in finding and interpreting reliable information. A participant stated

*When the doctor explains, I listen to what he explains about asthma and the medications because he’s the expert. If I don’t listen, I’ll miss the things that I don’t know or I’m not sure of. I have to listen carefully [to the doctor] because I don’t know where else to learn about these. I’m afraid, on my own, I may read the wrong information. I only depend on what the doctor told me.*

[Norley, 63-year-old Malay woman]
Norley praises the doctor as the subject expert in this quotation. She describes paying close attention to the doctor’s advice about her asthma management, emphasising the importance of doing so because she was afraid that, if she did not, she would read incorrect information. Other sources of formal information identified were asthma-related pamphlets and health talks. Participants described these sources as helping augment the knowledge shared by their doctors about asthma and how to care for it. A participant illustrated an example of such a source and explained

**Figure 27 Pamphlet on inhaler technique.**

![Pamphlet on inhaler technique.](image)

I like to keep the pamphlets (showing a photograph) on using the inhaler from the health clinics. And sometimes, I’ll go to the talks. The content is similar to what the doctor told me, but, the pamphlets and the [health] talks remind me of what I should always do to take care of my asthma, especially at home. It’s like revision (chuckled).

[Maiza, 31-year-old Malay woman]

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When asked where she obtained her asthma information, Maiza cites pamphlets and health talks she has attended (Figure 27). She states that, while the information she obtains from these sources is similar to what she has been told by doctors, she feels that these sources of information help to strengthen her understanding of asthma.

Informal sources of information about asthma and self-management practices also played an important role, especially recommendations from family members who had asthma. For instance, a participant explained his understanding of asthma:
I think I know why I get these attacks. My windpipe may be blocked because it swells up, probably when I’m allergic to something. So, the swelling closes the [wind]pipe, so my breathing becomes terrible. My sister told me about this; she has asthma too; way longer than I do. [Nasir, 33-year-old Malay man]

Nasir describes the pathophysiology of asthma in the above quotation, based on information shared with him by his sister. Nasir’s trust in his sister’s knowledge was reinforced by the fact that she too had asthma, and for a longer period than Nasir.

Parents were a common source of knowledge about asthma and how to care for it for those who had had asthma since childhood. A participant said

**Figure 28 A white hibiscus.**

[This is] white hibiscus (showing a photograph of the flower). The flower has medicinal properties. If I crushed it, it would give out sticky sap, and if I applied it to the chest, it stopped my cough. My mother used to do this since I was small.

[Maryam, 41-year-old Malay woman]

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Here, Maryam depicts the home-grown white hibiscus, which is thought to have cough-relieving properties (Figure 28). Coughing, a common ailment, can be one of the symptoms of an acute asthma exacerbation. Her mother used this therapy in her family, and Maryam continued to use it for her asthma.
Participants, especially those under 30, described reading about asthma on social media and were particularly interested in the experiences of others living with asthma. One participant described using Facebook to read and find inspiration from others’ experiences concerning how to live with and manage her asthma. She stated

*I searched Facebook [to] see how people talk about their asthma. When they talk about what they cannot eat, I like seeing if it’s the same issue [as] me. What they used when [their] breathing becomes not that great. I learned from them.* [Farra, 26-year-old Chinese woman]

In this case, Farra was explaining why she looks at Facebook. She describes how she learned about asthma management from other people’s experiences in the process.

**Understanding information on asthma and self-management**

- **The understanding was based on some scientific understanding**

Understanding of asthma and the natural course of the illness from a medical point of view was uncommon among participants of this study. However, there were exceptions. Some comments suggested understanding about asthma and self-management based on scientific understanding. For example, Omar, who was a cancer survivor, described his understanding of asthma:

*So, from what I read and the doctors, asthma is because my air pipe (pointing to the chest) is blocked, and the air cannot go in. This phlegm that blocks my air pipe is from my body, too (chuckled). Sometimes if the air I breathe is dirty like smoke, then the pipe acts up to get rid of this dirty air. So, this phlegm is like grease to trap the dirty air, but when it acts up too much, the problem comes. Too much phlegm, correct, right?* [Omar, 56-year-old Malay man]

In this quotation, Omar describes his understanding, in his own words, about asthma based on his reading and what the health professionals have told him. Another participant reported the understanding of asthma as a chronic disease that may occur at a young age or later stage of life. Such descriptions were
more common among participants with good asthma control.

Some participants were aware that asthma is a disease that is passed down from one generation to the next. Hannah, a mother of two children, commented on this:

*my asthma, it's definitely from one generation to another. Because my grandma has it, mom has it, mom’s siblings have it, (chuckled) after that my siblings have it.* [Hannah, 59-year-old Chinese woman]

Hannah, in this example, discusses how asthma is passed down through her family from generation to generation. This viewpoint was shared by other participants who had a family member who had been diagnosed with asthma.

Some participants reported some understanding that asthma might be related to other types of inflammatory disease such as allergy, sinusitis or a skin condition such as eczema. For example, Maryam illustrated with a photograph her skin problem due to known triggers (Figure 29) and explained:

*Figure 29 Rashes on the back of the hand.*

If I eat seafood, my lips will crack, then it will be itchy. Or my skin has this eczema rash (pointing to the photograph). It’s always the same place. So, if I have this [rash], I know I may have eaten something I cannot eat or touched something I’m allergic to. [...] But I saw my aunty, who has asthma had something like this [rash], but probably not as bad as me.

[Maryam, 41-year-old Malay woman]

As illustrated by Maryam, skin conditions such as eczema are commonly related to asthma. This knowledge of asthma was frequently gained by observing family members suffering from these inflammatory conditions and/or through the participants’ own experience.
Across the spectrum of age, gender and ethnicity, asthma triggers dominated the participants’ discussions about asthma, self-management and health-seeking behaviour. Many of the participants talked about food and drinks, particularly iced drinks. A few spoke about internal triggers such as stressful emotions that might trigger an acute exacerbation. As described in the previous chapter (Section 6.3.2), understanding the role of reliever inhalers in controlling acute symptoms was common among participants. However, only a few participants described the role of an inhaled preventer to control future asthma exacerbations, particularly in the presence of triggers. Commenting on the use of preventers and triggers, one participant, Omar, who described enjoying travelling with his wife, shared a photograph of his recent travels and said

**Figure 30 Omar is enjoying cold drinks without his symptoms being triggered by it.**

This medication (pointing to his preventer inhaler), I always take. So, my asthma is good now; gone are all the problems (pointing to his chest). Because I take this [preventer inhaler] every day, now, I can travel with my wife and enjoy an iced drink, look here! (laughs) [...] Not too long ago, I could only dream of doing all these.

[Omar, 56-year-old Malay man]

Here, Omar explains that his acute asthma problems were controlled by taking a daily preventer, even in the presence of triggers like iced drinks (Figure 30). Omar was able to enjoy iced drinks without difficulty, and he and his wife could enjoy travelling together, confident that he would rarely react to asthma triggers. Asthma that was well-controlled, based on this example, improved quality of life. Many other participants talked about the difficulties of managing triggers and the negative impact this had on their lives.
• **Health beliefs shaped understanding of asthma and perceptions of control**

However, commonly among participants in this study, health beliefs shaped understanding of asthma and perceptions of control. Asthma was believed to be a contagious disease by many participants. Participants described being haunted by the idea that asthma was contagious, especially if the predominant symptom was coughing. Some reported being told off for having an ‘infectious disease’ by others close to them or being frowned upon at work when they coughed. Saachi, who previously worked as a rubber tapper, spoke about how coughing was associated with tuberculosis in her accounts of the coughing misconception. She recalled

> I also don’t know how to explain to the people in the [rubber] estate why and how I got this asthma. I don’t have much problem with breathing. My problem is coughing, especially when it’s cold in the morning. We tapped the rubber trees as early as 3–4 am; that’s when I coughed a lot. […] One of the rubber tappers in my estate coughed for some time and later died [of] TB [tuberculosis]. So, people also thought I had TB (long sigh), and they were scared also. Those who didn’t know my problem gave me all kinds of looks when they heard me cough. [Saachi, 61-year-old Indian woman]

Saachi, who previously worked as a rubber tapper, speaks here about how her asthma symptoms were misinterpreted. Coughing is widely accepted as a physical indicator of illness and, specifically in this setting, tuberculosis. Saachi highlights how such widely held beliefs result in stigmatisation. She further acknowledges that her lack of understanding makes it difficult to accurately explain her ailment and the physical symptoms that accompany it. This difficulty in explaining asthma to people was also expressed by other participants who could not describe their condition accurately to others.

In terms of therapies, complementary and alternative medicine were commonly identified and related to participants’ beliefs. A common belief among participants in this study was that complementary and alternative medicine reduced acute asthma exacerbations. Amin, a retiree, provided an
example of how he used the ‘cupping method’ alongside his inhaler therapies and attributed his improving asthma control to both of these factors:

My asthma attack was reduced not just by taking the inhaler, but also, I practised [body] cupping. I went for [body] cupping to get rid of the toxin from the blood. When the blood is out, we could become healthy. It’s one of the Prophetic Therapies, I think, and we must believe in its healing power. [Amin, 66-year-old Malay man]

In this quotation, Amin attributes the control of his acute asthma symptoms to the ‘cupping method’. He describes how such methods are linked to his practice of Islam and his understanding of the Prophet Muhammad’s teaching. Complementary and alternative medicine was essential for Amin and several participants, because the approach was anchored in their religious beliefs and identity.

- **Factors affecting understanding**

Participants described factors related to i) patients and ii) healthcare professionals that influenced the process of understanding information once they had found relevant asthma or health information. These factors were reported as particularly relevant when receiving information about asthma and its management from the healthcare system (for example, pamphlets or interaction with health professionals).

In patient factors, language was identified as a key challenge in understanding information about asthma and its management. Participants pointed out that paper-based information provided at the healthcare centres was mostly in Malay or English. Although most reported the ability to read Malay, some struggled to understand these languages and described the need for services and/or asthma information packs in their native language to help them with their asthma care. One participant expressed her need for Mandarin-version written information, as she struggled to read Malay and had to ask for help with translation:
It [will] be good if there’s a Mandarin version of this [action] plan. It’ll make my life easier. If the doctor speaks to me in Bahasa [Malay language], I can understand a little bit. But, reading this [the asthma action plan] in Bahasa, I don’t quite understand. I have to ask for my husband’s help to translate. [Lin, 22-year-old Chinese woman]

Other participants used internet tools, such as Google Translate, to interpret the information given to them. However, among participants who could read and speak the common Bahasa Malaysia language, some described difficulty understanding the formal Bahasa Malaysia language used in asthma information. One participant, for instance, described the written asthma action plan as wordy and difficult to understand.

I can speak and read Malay [language], but that [asthma action] plan has too many words (chuckled). [Lock, 78-year-old Chinese man]

Healthcare professionals were vital in facilitating understanding, and the lack of effective doctor–patient communication – verbal and non-verbal – was another challenge to understanding information about asthma and its management. For example, one participant described how doctors’ lack of explanation made him question his prescribed treatment:

They [the doctors] will say do this and that, but they don’t even explain why. They said I have asthma and that I need to use the brown inhaler every day. But why? If I’m not sick, why should I use it? [Amin, 66-year-old Malay man]

Amin emphasises the lack of discussion about the asthma treatments he was prescribed in this scenario. It was not clear, according to Amin, as to why he was required to use the preventer inhaler daily even when he was not sick. Amin’s remark reflects his misunderstanding of the significance and function of the preventer inhaler prescribed to him.

Some participants recalled their struggles to understand the conversation with their doctors in consultation because of medical jargon. Talking about this issue, a participant commented
The doctors like to use these fancy words [medical jargon] and English too. I find it difficult to understand what they say when they do this. [Yatim, 72-year-old Malay man]

Yatim highlights the combined problem of healthcare professionals using medical jargon and English terms that he does not understand.

Other participants observed non-receptive body language from their healthcare professional, which deterred these patients’ efforts to clarify information about asthma or the management plan. A participant shared her experience:

When I came for follow-up, the doctor barely looked at me. That’s not really welcoming. I don’t think that doctor is the type who wants to explain anything to me, so even if I don’t understand anything, I’ll just keep quiet. [Rose, 61-year-old Malay woman]

**Appraisal of information on asthma and self-management**

Most participants did not explicitly evaluate information or check the authenticity of information before applying it. Most participants would say they never considered doing so. In the context of their interactions with the healthcare professionals, most participants described ‘just following’ the instructions given to them. One participant described the paternalistic culture she had experienced, which led to such behaviour. She recalled

I have been an asthma patient for the past 25 years. For many years, I took the medicines [which had been] prescribed by the clinic. I did what I was told to. I didn’t question about right or wrong [on] anything the doctor told me. I once asked [the doctor] about my breathing. I couldn’t remember what exactly it was, but his words are deeply engraved in my head: ‘Are you the doctor, or am I?’ You see, I didn’t go to school (trying to cover part of her face with her saree). I was embarrassed and [I] think I made a fool of myself by questioning him. It was many years ago. I know they are nicer now [than before], but since then, I never asked or questioned. So, I just follow. [Saachi, 62-year-old Indian woman]
In this case, Saachi describes an unpleasant experience with her doctor when she inquired about her health. This experience shaped her attitude towards and communication with her practitioners. Even though this incident occurred a long time ago, and she recognises that healthcare professionals’ attitudes have changed, Saachi continues to play a passive role in this relationship.

Other than health information provided by healthcare professionals, typically, information was assessed compared to experiential knowledge gained through living with asthma. For example, one participant provided an example of balancing health information with her own experience with illness, as well as the experiences of others. She stated

Figure 31 The haze season.

If I see posts on social media and everyone else agrees on it, then probably it’s true. People said that the air-conditioning system in the car makes people cough. It’s the same with me, but I still use it at times. Like during the haze (showing a photograph), you cannot even see the sun, meaning it’s awful. So, I must [switch] on the air-con [air-conditioning system] and roll up my car’s window. My asthma with haze is worse than with the air-con. So, I have to choose the lesser evil. But one person is different from another, so you need to understand your own body.

[Naemah, 38-year-old Malay woman]

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Naemah took a photograph from her workplace during the haze season to illustrate her point of view (Figure 31). She describes how she weighs the information about asthma triggers she finds on social media and compares it to her own experience before acting on it. Similarly, most participants did not evaluate health information, though some used their experiences to assess asthma information and decide whether to act on it in order to care for their health.

**Application of information on asthma and self-management practices**

- **Established self-management practices were a mixture of science-based knowledge, social norms and culturally determined health practices**

In terms of applying knowledge about health, social norms and culturally determined health practices influenced the self-management decision-making process. Mixed use of prescribed medication from the health services and complementary and alternative medicine or home remedies were discussed in most interviews, particularly among people with uncontrolled asthma.

In this study, complementary and alternative medicine and home remedies were typically reported as being used to treat general feelings of being unwell, regardless of the cause, to prevent worsening of health. These therapies were found to be effective by most participants. The language used to describe being unwell varied. Participants, particularly of the older age group, used knowledge, common social expressions and ethnically related phrases to describe being unwell, such as ‘nafas tak sedap’ [unpleasant breathing] and ‘badan rasa tak senang’ [the body is feeling uneasy]. Participants of Malay and Chinese ethnicities used ‘badan berangin’ [the body feels windy], as such expressions were commonly used in these communities to describe the onset of general health decline. Several participants who described such feelings of general unwellness reported a subsequent acute event of asthma exacerbations, though this association was not always clear.

In the photo-interviews, some participants took photographs of the complementary and alternative medicine and home remedies that they used.
to counter the feeling of being unwell. When participants reported beginning to feel any discomfort before the actual chest tightness or breathing difficulties, ointment was often applied to the chest and throat. A participant described the use of ointment at the onset of her symptoms (Figure 32):

**Figure 32 Commonly used ointment.**

![Symfony Tisana Chest Ointment](image)

*Many people know about this. My friends asked me to use it, and I tried, this [ointment] relieved me (pointing to her chest). I put it on my chest, my back. I’ll ask my kid to apply over there (pointing to back). When I start to feel uncomfortable, I will use it.*

[Letchumy, 54-year-old Indian woman]

Letchumy used this example to explain how she used the ointment on her chest when she became uncomfortable. According to Letchumy, the motivation for using such therapy was based on recommendations from friends. Participants were keen to follow the suggestions of close friends for dealing with acute symptoms, or they copied strategies used by other family members. One participant said

**Figure 33 Another commonly used ointment.**

![Vicks VapoRub](image)

*My mom uses Vicks. So, since I was a kid, I have practised rubbing Vicks (showing circular movements on her chest), as my mom did. This thing (pointing to the photograph) actually helps. Really. It helps with asthma, especially when you are just about to feel it, the tightness.*

[Maiza, 31-year-old woman]

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In this case, Maiza describes the use of another type of ointment, *Vicks*, as mirroring what her mother used during the early stages of an acute asthma
exacerbation (Figure 33). Some who subscribed to the concept of *Yin and Yang* used warm water to counter asthma attacks. The *Yin and Yang* concept is based on the philosophical understanding that natural elements of the world have two opposite natures, like hot and cold, that constantly change towards dynamic balance and harmony [218]. The ‘hot and cold’ belief in asthma was shared by participants of Chinese and Indian ethnicities in this study. They talked about the positive effect of drinking warm water in alleviating asthma symptoms. Talking about the ‘hot and cold’ belief from the perspective of the *Yin and Yang* concept, Farra, a Chinese woman, explained

*If I start to feel uneasy, I’ll drink warm water. That’s why it’s always in my bedroom. Night-time can be cold. It [the warm water] can make my body feel warm. It’s easier a bit to breathe. You know, like the Yin and Yang. Hot and cold, same one. We Chinese believe this: the opposite of elements. So, this asthma illness, people believe you get when you’re cold. So, you need hot to counter.* [Farra, 26-year-old Chinese woman]

In this example, Farra draws on her cultural understandings and beliefs of the world around her to interpret her own symptoms and to manage them within this specific cultural context. Other participants, particularly those of Indian ethnicity, used descriptions of *ayurvedic* medicine to make sense and manage their symptoms. *Ayurvedic* medicine is commonly used among the South Asian population and is based on the concept of maintaining equilibrium and adopting a holistic approach in disease management [219].

Several photographs were taken of complementary and alternative medicine and home remedies used to counter acute asthma exacerbations. Participants reported how close friends and family members actively recommended some of these therapies. For instance, one participant photographed the traditional herbal medications introduced by her neighbour (Figure 34). She explained
In this example, Letchumy used crocodile meat and accompanying ingredients to alleviate her symptoms. However, she explains that she avoided discussing such therapy with her doctors because she feared they would not agree with her choice or believe the relief she received from consuming it.

They [the doctors] are not going to believe me [that] this [the crocodile meat] is good for my asthma. People always tell me they got told off by their doctors if they told the truth about what other things they took at home for asthma. [Letchumy, 54-year-old Indian woman]

In this example, Letchumy drew on the experiences of others with their doctors to decide not to disclose her usage of complementary and alternative medicine for asthma.

Despite the numerous reports about using complementary and alternative medicine among participants of this study, several participants reported using a reliever inhaler to treat classic acute asthma symptoms, such as shortness of breath, chest tightness, wheezing or coughing. These participants described their understanding of the function of the reliever inhaler and most provided an explanation that the medication was used to open up the airway to prevent the symptoms leading to an asthma exacerbation. As one participant put it,
It usually starts [with] just [a little bit of] cough. I just use the blue one [reliever inhaler] to open up the chest [airway]. It always works for me. [Teng, 59-year-old Chinese man]

Teng gives an example of his action at the first sign of symptoms. Similar understandings of how the inhaled reliever medication exerted its effect on the airways, as described above, were shared by many participants.

Only a few participants described the importance of the preventer inhaler as a steroid inhaler that functions by controlling inflammation and making the airway less susceptible to react to triggers. A participant emphasised this issue:

*You have to follow the instructions [for] the medication like they say, the brown [preventer inhaler], the blue [reliever inhaler]. [The] brown [inhaler] is important; take it every day. The blue [inhaler] is to be used when necessary. So, this is how to prevent [asthma] attacks.* [Hannah, 59-year-old Chinese woman]

The use of the inhaler’s colour in this excerpt is an important feature, as the colour of the inhaler is used to indicate the type of therapy, facilitating understanding and use of asthma therapies. Although Hannah rightly pointed out the importance of daily preventer therapy, she also revealed that sometimes, feeling tired of taking the inhaler, she had made attempts to stop using the medication, echoing many discussions among the other participants who used the preventer inhaler regularly. Hannah explained that her decision was based on the advice she understood from her doctor. As she further described,

*I stopped this [the preventer inhaler] for about two weeks, I think. I thought I was OK for quite some time; why not try it? I try hor [a common expression to emphasise opinion]. Then, recently [during] Chinese New Year, I ate all sorts of things, then it [wheezing] started again. Then I feel the need to follow again the daily regime (showing the brown inhaler and putting it near the mouth as if using it).* [Hannah, 59-year-old Chinese woman]

In this quotation, Hannah highlights her trial of not taking the daily preventer inhaler, particularly after her symptoms had improved over time. Self-
management is demonstrated by the act of starting, pausing and restarting medication depending on symptoms, rather than waiting to be informed or allowing one’s condition to deteriorate. However, as with other participants who used the daily inhaler, such self-management decisions were made through trial and error rather than with the guidance of health professionals.

Some participants reported self-treatment with oral therapies (including oral steroids and oral salbutamol). This practice was observed to be more common among those who had poor asthma control without any regular follow-up consultations and with frequent use of emergency services. The oral therapies for asthma described by participants in this study were reported to be available without the need for prescriptions at pharmacies, being prescribed by private general practitioners or given by the emergency centres during acute attacks.

The participants who discussed their self-treatment practices were found to know little about the long-term risk of these oral therapies. Many of these participants only discussed the short-term side effects of these oral therapies. For example, some had experienced ‘shaking’ episodes from oral salbutamol, but they continued to take it in response to an asthma exacerbation because they perceived it to be effective. With oral steroids, a participant with Type 2 diabetes mellitus reported a rise in blood sugar level during usage and weight gain. Another participant recalled

*I put on weight, I think, because of the medication, because of those six [steroid] pills. [...] Every time I go to the emergency [department], they’ll give these [steroid] pills. Sometimes, I take the gas [nebulisation], one week four times, right. Every time, they gave and asked me to finish it. So, now I only take for one or two days or when I think I’m OK only.* [Kiyya, 30-year-old Indian woman]

Kiyya drew on her experience to describe the side effects of steroids. She applied the knowledge about weight gain in this interview based on a discussion she had about steroids’ side effects with another asthma patient she had met in the clinic’s waiting room. She had dismissed the comment at the time, because she had just been diagnosed with asthma and did not think
the weight gain issue would apply to her. Consequently, she decided to shorten the prescribed course by a day or two or stop when she felt better.

A common theme shared by participants in this study was that nebulisation was an appropriate ‘step’ to control an attack, while a small number of participants perceived that nebulisation is the ‘best step’ to suppress an acute exacerbation. Illustrating the latter case, Nasir stated

*I’ll go to the emergency [department] when I have an [asthma] attack, and my symptoms usually disappear [with] a round of neb [nebulisation]. Good enough for me, [as] the neb controlled my [asthma] attack. For me, the best treatment would be to get the nebulisation when I need it.* [Nasir, 33-year-old Malay man]

Nasir explains in the above quotation that nebulisation is a go-to option during an acute asthma exacerbation, so he does not believe he needs to see any healthcare professionals while in remission. Some participants reported being advised to seek medical attention right away if they experienced an acute asthma exacerbation. The advice to seek immediate medical care engendered reliance – and anxiety if they could not access care, because then they would not know what to do.

**In summary**, the application of asthma and self-management skills was heavily influenced by norms within the immediate social network and experiential knowledge. The most commonly used strategies revolved around what participants thought worked best and how they interpreted the asthma knowledge they received.

- **Challenges in using guideline-recommended self-management**

In general, it was reported that stigmatising experiences influenced self-management decisions. Sports and physical activities, such as playing football, were identified as essential activities in embodying health identities, particularly for two young men in this study. Using an inhaler before a game or during a match demonstrated ‘weakness’ and invited unwanted social
reactions for these participants. One participant shared a photograph of a football pitch where he used to play (Figure 35) and said

**Figure 35 Keeping active and health identities.**

![Football pitch](image)

> When I feel like I’m about to be breathless, and my breathing starts to be fast, I’ll continue playing. Other people can’t see it, and I don’t want to ruin my reputation. Or else, no one wants me in their team if they know I’m sick. I’m a better football player than anyone on that field! Besides, for anyone who is running, their breathing will be fast. So, it’s normal. There’s no big deal about it, and my breathing will be back to normal by the end of the game.

[Yeop, 28-year-old Malay man]

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In this quotation, which is accompanied by a photograph of Yeop’s team practising from a distance, he discusses concealing his symptoms as a strategy to avoid unwanted attention among peers. Another participant who described a desire to appear physically fit expressed a similar use of concealment.

Another challenge of implementing guideline-recommended asthma care was the lack of awareness about written asthma action plans, as most participants did not seem to be aware of or know what a written asthma action plan was. A written asthma action plan is recommended in national and international
asthma guidelines to support self-management and improve health outcomes [5,14]. During the interview, participants were shown an example of an asthma action plan. Most participants described it as ‘unfamiliar’, as they had never seen one before. The interview was the first time many of them had heard of or seen an asthma action plan.

A participant inquired about the written action plan shown to him during the interview:

This [plan] is unfamiliar to me. I have never heard of it (looking and sounding very surprised) or seen this (pointing at the written asthma action plan). What’s the use of it? [Amin, 66-year-old Malay man]

Amin’s reaction to seeing the written asthma action plan was common among the participants in this study who had never been given an asthma action plan. In addition, there was a shared perception among the participants that doctors chose which patients to provide with a plan. They argued that such a decision might be due to the complexity of the plan and the time needed to help patients understand the plan.

Only a few of the participants were able to recall, albeit incompletely, verbal instructions given to them by their doctors on what to do in the event of an exacerbation. Remembering step-by-step instructions without a written reference was challenging, according to other participants who shared similar difficulties in remembering instructions given to them. Some participants described following the only step that they remember: go to the hospital. A participant described this. She said

After seeing the doctor, I remember when the discussion was around having to use the inhaler. Is it 3 to 4, or is it 4 to 6 times? I can’t exactly remember. I needed to do this when I started to feel my breathing was not easy. There was another step before that, but I can’t remember now. You see, how difficult it is? [...] When I first heard it, of course, I remember. When I got home, I did not have the attack right away. Maybe a week or a month or two later. By that time, I already forgot what the doctor told me. All I know is
Salmah’s description is related to the characteristics of asthma, which is an illness that can vary in severity and duration at different times. The time lapse between exacerbations made it difficult for Salmah to remember what to do in the event of an exacerbation other than seeking expert help at the hospital.

Only four participants had been prescribed a paper-based asthma action plan. They discussed challenges around language and wordiness as well as the difficulty of not losing a paper version of the plan. They described the need to repeat the teaching on how to use the plan.

Guna, a 48-year-old Indian man who had been given a written action plan in the past, commented that it was useful. However, he complained about the struggle to find the paper version during an exacerbation. When asked about the challenges he faced, he described his difficulty in understanding the plan and how family members helped him with it. He complained:

They teach one time only, how [am I going] to understand? Maybe [if they] teach my wife too, it will be good. She’s the smart one (laughed). [Guna, 48-year-old Indian man]

Another participant described the difficulty of keeping a paper-based asthma action plan. She recalled:

I lost it if it’s paper like this (pointing to the asthma action plan). Once my kids took it out from my handbag and scribbled on it, and it’s gone. It’s just a white, about [the] size of an A4 paper [that you] cut into half, I think (chuckled). [Lekha, 31-year-old Indian woman]

Another participant, who had just been provided with a written asthma action plan, expressed a similar view about the frequency of teaching the plan. She said:

Useful knowledge la (common expression in spoken language to emphasise opinion) this plan, to guide what to do at home. But I
Hannah acknowledges the promising role of a written asthma action plan for self-management at home. She emphasises, however, the need for repeated education sessions, as the plan was a new thing for her and she struggled to understand everything in just one session.

Overall, formal social support could engender a positive understanding of asthma, which helped some participants adopt a positive attitude towards guideline-recommended care. One participant, who joined a patient support group to improve physical health, described how the weekly gatherings had helped him embrace his identity as a person living with asthma and enabled him to empower others (Figure 36):

*Figure 36 Community support.*

I took this photo during one of our weekly gatherings. Usually, we start [with] a session by the doctor or the pharmacist. They gave talks about health, including asthma, that’s where I know everything about how to take care of health. So, when other members [of the club] who don’t have asthma listen to [the] talk about asthma, they know a little bit about it. The highlight of the day will be snack time! The club members take turns to organise this. Sometimes they get together and cook at their house, so we will enjoy some home-cooked meal. It is during mealtime that we chat; we share stories – good and bad. We feel we belong to something, and we are not ashamed of who we are – a person with asthma or diabetes or whatever it is. So, as a person with asthma, I actively find new asthma patients to join this club. It is not just for them to know better about their illness but to be among the people who understand what it is like to live with breathlessness.

[Omar, 56-year-old Malay man]

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Omar uses this example to describe a social support system in which he was embedded. The support he received was through socialising, including eating and listening to each other. Being in a shared space with others who live with asthma and other chronic illness, his identity as someone living with an illness became normalised and less stigmatised. By creating this positive environment, he felt that he was understood as someone living with asthma. However, across the study, social support was absent, highlighting the gap in asthma care in this population.

Specifically, on strategies to improve awareness, all study participants agreed that a written asthma action plan must first be prescribed by a healthcare professional to all patients. Some participants expressed a preference for their doctors to prescribe and implement the asthma action plan education, because the doctors were the ‘experts’ in this area. One participant shared his opinion on this:

*I still think the doctor should teach this (pointing to the asthma action plan); they [are the] experts, mah [Chinese word used to emphasise certainty]. Sometimes, if I ask a lot [about] asthma, the nurse [will] say, ‘I’ll check with the doctor’. Cannot hor? [Chinese word used to seek out agreement]. So, the doctor is the best person.* [Lock, 78-year-old Chinese man]

In this example, Lock reflects on the doctor’s role as a health expert and the best person to prescribe a self-management plan. Other participants argued that time constraints could make it difficult for doctors to prescribe and teach patients about such a plan. However, some participants suggested that nurses and pharmacists could take up this task and shared ‘pleasant experiences’ of being educated by pharmacists and nurses in other areas of asthma management. One participant gave an example of her experience being taught by the pharmacist how to use an inhaler:

*I don’t think doctors have the time. Probably need to train the nurse or the pharmacist to do this [prescribe an asthma action plan]. The pharmacist took the time [to] teach me to use the new*
Salmah describes the process of learning how to use an inhaler, when the educator spent the time necessary to carefully teach her the techniques until she was able to master them. Two participants who had been prescribed a written action plan agreed that empathy and tailored support should be at the heart of the education initiative to teach about an asthma action plan. One comment best captured the participant’s feeling about this:

Whoever does it [patient education] must have the patience and understand that not all patients find learning easy. It cannot [be] just one way to teach all asthma patients. That cannot be the case.

You and I know [that] some patients know more about their asthma, [and] some know very little. [Nina, 39-year-old Malay woman]

In this quotation, Nina describes the need for health professionals who provide asthma action plan education to understand and recognise the learning needs of different patients, particularly the depth of each patient’s knowledge about asthma. A number of participants, who were concerned about their inability to learn and understand new things, described help they received from family members such as spouses. A participant suggested

Usually, my wife comes with me to the [medical] appointments. She understands all these instructions better than I do. She listens very well (chuckled). I need my wife to learn so I can learn from her, and she’s good at reminding me to use this [asthma action] plan when I need to. [Teng, 59-year-old Chinese man]

In this example, Teng emphasises the importance of his wife learning about the asthma action plan alongside him. She will become not only his point of reference but also a source of motivation to use the plan when the need arises. Help from children was also identified by participants who lived in multigenerational households. One participant suggested
Maybe if they teach my daughter too, she lives with me, she can help me, like understand this (pointing at the asthma action plan).

[Rosmah, 67-year-old Malay woman]

As in this example, other participants identified people within their family or peer circles who could help them use the asthma action plan. This finding highlights the fact that support does not only come from healthcare professionals. Participants identified the range of key figures they had worked with to support them and find ways to improve their understanding and use of such plans.

In terms of an alternative format to a written asthma action plan, most participants suggested that the use of images would be helpful:

But a bit more images is good. You know, like anime, so the steps will be like a story and easy to understand. But this paper is also black and white. Not interesting. [...] The mobile app, that’s useful too, [as I] can refer to it any time. [...] Maybe we can put a video on how to use the inhaler. I seldom need [to] use my inhaler, but I have sort of forgotten when I need to. [Lin, 22-year-old Chinese woman]

Anime is a Japanese term which originated from the English word ‘animation’, and which is commonly used outside Japan to refer specifically to Japanese animation. Anime has grown in popularity in Malaysia since the early 1990s, particularly among schoolchildren and young adults, due to cultural similarities in anime’s characteristics to the Malaysian context [220]. Drawing on familiar cultural references like anime, Lin describes how images can deliver the steps of the asthma action plan in a simple, easy-to-understand format. She also believes that images and colours would make the plan more appealing, which was echoed in other interviews. She adds that technology such as mobile apps could be an effective, innovative format. Other participants also suggested that the use of technology could improve the accessibility and use of asthma action plans. Another participant shared similar views about delivery of an asthma action plan using a mobile application:
If you have a video or something interactive on how [to] use this plan, maybe easier, for example, on a phone app. Everyone has a phone, [and] they carry their phone around. I don’t think people carry hospital paper around like this plan. We can have this information in the app. [Yeop, 28-year-old Malay man]

Using the example of an app, Yeop points out the ease of access to a plan embedded in a mobile phone. Other participants who shared similar views as Yeop commented that they wouldn’t lose a plan on a phone, as they might a piece of paper, and the mobility of an app would mean that they would always have it with them. Mobile apps were not only for the younger patients; older participants also saw the potential benefits. Some of these participants described their willingness to learn from younger family members who lived with them.

Paper-based asthma action plans were still preferred by a small number of participants. Some were older people who felt that technology was too much ‘hassle’ for them. They had smartphones, but only used them for basic functions like making and receiving calls. Others owned smartphones but did not have internet access. While they preferred paper-based asthma action plans, they suggested that a smaller plan using sturdier card would be more practical. A participant who suggested a picture-based asthma action plan in a paper format said

> Maybe this plan should have fewer words. Put pictures, perhaps – maybe use stiff paper and make it small like the credit card. So [I] can put it in handbags (laughed). If you can make [it] more colourful and attractive, people feel a waste if you want to throw it away. [Zainab, 73-year-old Malay woman]

Zainab, a participant who preferred a paper-based asthma action plan, wanted a credit-card-sized version of a picture-based action plan. She describes a colourful, credit-card-like version as convenient to carry in her handbag and appealing enough not to be thrown away.

In summary, this section has highlighted the importance of social support for living with asthma and using an asthma action plan. The findings suggest that
different and innovative formats of an asthma action plan might improve accessibility and use.

7.5 **Discussion**

7.5.1 **Summary of findings**

In terms of access to information about asthma, participants used formal and informal sources to access information about asthma and self-management. Struggles with language (both ‘jargon’ and lack of translations) affected the understanding of written information, while good communication with a healthcare professional could help overcome this. Understandings about asthma and perceptions of control were predominantly based on health beliefs. Participants had limited clinical understanding of asthma and its management. In the context of appraising health information, most participants ‘just followed’ the health information that they found or were given and did not explicitly describe strategies to evaluate or check accuracy, though a few drew on experiential knowledge to help validate advice. Established self-management practices were mixtures of scientific knowledge and culturally determined health practices.

Few participants had been given a written asthma action plan or were aware of their use. Those with experience of using a written asthma action plan described challenges in understanding and its practicality in their daily lives. Recommendations to improve awareness, adoption and use of a written asthma action plan included active provision by healthcare professionals supported with tailored patient education and training, family involvement (if appropriate) and an innovative format of the asthma action plan through a technology platform. Social peer support had a positive influence in evidence-based self-management decisions.

7.5.2 **Strengths and limitations**

Using the health literacy framework [36] ensured I used a structured approach to inform the analysis. However, I acknowledged that using a pre-determined framework might overlook the interpretation of novel themes outside this
framework. Therefore, to be holistic in my interpretations, as described in Section 7.3, I explicitly looked for novel views and unexpected themes to be included in the analysis. For example, one of Sørensen’s domains of health literacy is ‘Appraise’, but there were no codes in any of the interviews that described Sørensen’s process of appraising health information. Instead, participants described ‘just following’ the information they received and/or evaluating the credibility of health information based on their own experience or the experiences of others around them. These quotations were coded as ‘non-conforming’ under the domain of ‘Appraise’. The use of photographs, and the interview prompt centring on the element that the participants could not photograph, allowed them to establish the interview agenda outside of the health literacy framework. The findings of the narrative analysis in Section 6.4.2 complement the framework analysis. As an interpretative method, a narrative approach to analysis helps explain the meaning of living with asthma and the factors influencing decisions about self-management within the social context as participants understand it: for example, the impact of an engendered social role (e.g., an obedient daughter-in-law) on the embodiment of the identity of a person with asthma and caring for their own health, including their mental health (Section 6.4.2). The narrative analysis helps me think beyond the health system to how health literacy operates at the societal level and in a more holistic manner, beyond Sørensen’s domains of health literacy. The population sample in this study is not representative of people with asthma and limited health literacy in the general population. However, highlighting the challenges of limited health literacy in asthma care and its impact on health decision-making can create awareness and initiate system actions to narrow health inequality gaps in asthma care [221].

7.5.3 Interpretation of results in relation to the domains and comparison with the literature

Reflection on the sources of information people use to access information on asthma and self-management

Healthcare professionals were an important formal source of evidence-based information regarding asthma and its management. Participants in this study
relied heavily on their healthcare professionals for reliable information about asthma and evidence-based management. However, an implication of this reliance might be that their access to such information is limited to such encounters. Various (largely unpublished) audits done in Malaysian primary care settings found that close to half of the study respondents had clinical consultations lasting between 11 and 20 minutes [222]. However, another study examining healthcare workforce per capita showed a ratio of 15.1 professionals per 10,000 in urban areas, suggesting that consultation times may be considerably shorter [223]. In such short encounters, little adequate health information is likely to be exchanged between doctors and patients in many clinical practices. Due to time constraints, healthcare professionals may selectively provide health information only to some patients, such as those with poor disease control or those they perceive could quickly understand the health information [224-226]. Such selection may overlook those for whom it is feared that a longer explanation may be needed and, inevitably, widen health inequalities. This challenge might explain the finding in this study that most participants did not receive a written asthma action plan and only received partial advice verbally. In a survey conducted in primary care settings in Klang, which involved participants with asthma and limited health literacy, it was reported that only 29.1% of the study participants received some form of education on asthma action plans [1]. Of these, only 7.1% received a written plan [1], which correlates with the findings of this study.

Other sources of evidence-based information about asthma and its management highlighted by the participants in this study were written information, but the lack of translations of such information limits its use. Limited health literacy is not merely an individual trait; it is also influenced by the characteristics of society and is a potential marker of multiple life circumstances, such as systemic and socio-cultural challenges, that contribute to limited health literacy [49,76,227]. It tends to disproportionately affect vulnerable populations, including people with lower educational attainment, those of lower socioeconomic status, people from ethnic minorities, and people whose spoken language differs from the majority population. For example, the
findings of this study highlight the issue around health information in Malaysia being printed in Malay and English languages. Since over a third of the Malaysian population probably speak other languages [88], such as Mandarin and Tamil, this may hinder their access to the information on health promotion and disease prevention. Internet-based translations of written health information provided by the health system were used by participants in this study; however, such translations may not accurately reflect the nuanced ethnic descriptions of illness [59,228]. Another problem highlighted in this study was the language adopted by healthcare practitioners in communicating health information. This study identified how language played a vital role in facilitating – or inhibiting – knowledge exchange between the patients and their sources. Despite being a multilingual nation, interpreter services in the Malaysian healthcare system are limited, echoing challenges reported in other healthcare services [144,229]. Typically, services depend on healthcare professionals to recognise and address the language problems [224,225], commonly by using family members as translators, which is not ideal. Information tailored to the patient’s health literacy needs is more likely than generic information to be understood, adopted into positive health behaviours [230,231] and applied in real life. Tailoring asthma action plans and information to health literacy needs is thus essential, particularly in supporting understanding of asthma action plans and their use among the participants of this study.

**What do asthma and self-managing their asthma mean to people with limited health literacy, and what are the factors affecting understanding?**

With limited access to evidence-based information, it is unsurprising that participants lacked a comprehensive understanding of asthma and its management. A study by Edwards et al., examining the development of health literacy among people with long-term conditions, suggested that the process was a trajectory [56]. In this model, people with long-term conditions (regardless of health literacy level) initially developed health knowledge by actively searching and critically appraising health information [56]. Such
processes for understanding their own health were translated into practice as patients became active communicators and decision-makers about health, including adopting evidence-based self-management strategies [56]. Difficulty with this process may be one of the reasons that the current study’s participants adopted a passive role in their encounters with health professionals and in searching for information for their health benefit.

Stigma may be another reason for assuming such a passive role. For example, the participants in this study reported understanding their asthma and managing it based on their own health beliefs but described challenges in communicating with their healthcare professionals. They feared, for example, negative reactions from the healthcare professionals regarding the use of complementary and alternative medicine. The lack of discussion and knowledge exchange about the reasons behind complementary and alternative medicine use from the patients’ point of view, and its role in asthma management from the practitioners’ point of view, may deter holistic understanding about asthma management. It has been shown that healthcare professionals’ reluctance to have conversations with patients about complementary and alternative medicine may stem from lack of a trusting relationship, personal disapproval of complementary and alternative medicine, and a lack of evidence, which left healthcare professionals uncomfortable discussing the topic [232]. Thus, training may help professionals understand the patients’ perspectives and provide the desired level of information and care for patient needs [232].

**Do people with limited health literacy appraise health information?**

A key challenge for the participants in this study was a lack of analytical skills. Most described how they ‘just followed’ advice, while some highlighted the use of experiential knowledge to appraise information. Lacking in ability to assess or evaluate health information, people with limited health literacy may find it challenging to navigate the information available on the internet and social media. This study revealed that participants looked to the internet (especially social media) to find others with similar illness experiences and used these
stories to learn new strategies or confirm that their health behaviour was appropriate. However, without the ability to evaluate the vast amount of information on the internet and social media, people with limited health literacy might not be able to use the internet safely to care for their asthma and benefit from this information. There is a potential risk of exacerbating the spread of false information and fearmongering advice against evidence-based asthma management [233]. According to one study, one way of developing health literacy abilities and skills is for patients to practise finding and applying information about their health [56]. With assistance from their healthcare professionals, or trained lay health worker such ability has the potential to increase health literacy [56,121].

**Reflecting on how asthma and self-management information is being applied in daily life**

As described in the findings of this study, participants applied information by deciding what worked best for them. Knowledge, health beliefs, and illness experiences from friends, family and social media were the most influential sources and most used type of information about asthma and its management among the participants in this study. Such knowledge and beliefs might not paint an accurate description or adequately describe asthma and self-management from an evidence-based point of view, as these beliefs were grounded in experiential information. Personal knowledge and experiences about health and beliefs may be embedded within social-cultural norms and affected health practices [76]. By contrast, healthcare professionals’ knowledge about asthma and self-management derives from scientific understanding and evidence from robust clinical trials [5,14,120]. Thus, patients must make sense of the knowledge they have received from health professionals and balance the benefits of applying it compared to what they used to know, do or prefer.

Asthma self-management decision-making and health practices among participants in this study remained aligned with their social norms and health beliefs, highlighting the challenge of embracing ‘evidence-based’ norms that
could improve asthma outcomes. Health beliefs in Malaysia are commonly influenced by one's ethnicity. Among those of Malay ethnicity, primarily Muslim, their health beliefs were highly influenced by Islamic teachings and Prophetic medicine (e.g., treatment with herbal medicine and spirituality). The Yin and Yang concept is commonly used for those of Chinese ethnicity and is central to traditional Chinese medicine. The concept is based on the philosophical understanding that natural elements of the world have two opposite natures (e.g., hot and cold) that constantly change towards dynamic balance and harmony [218]. Those of Indian ethnicity commonly used descriptions of ayurvedic medicine to make sense of and manage their symptoms. Ayurvedic medicine is well known worldwide and is based on maintaining equilibrium and adopting a holistic approach in disease management [219]. However, it was found that the 'hot and cold' belief in asthma was shared by participants of Chinese and Indian ethnicities in this study. In real life, it is not easy to differentiate the origin of certain health beliefs due to cultural exchange and assimilation that has been observed between the ethnicities for more than 200 years [234].

It may take time for health beliefs and culturally determined health practices to shift towards an evidence-based approach to health. However, acknowledging patients' views, and empowering people with limited health literacy living with asthma to understand their health and management based on evidence, has shown promising results [235]. A recent review highlighted social media as a powerful channel for health communications to promote evidence-based health practices but also cautioned about the lack of reliability of its content, confidentiality and privacy of personal information [236]. Apart from the support and facilitation of health professionals, supporting superusers (users who write a large number of posts in online health communities) is one option to promote such initiatives. Superusers have the potential to reach a wide population, and supporting such communities could be a cost-effective approach to providing accurate information about asthma and awareness about guideline-recommended practice [236,237].
Views and experiences on evidence-based asthma management and how it can be supported

In this study, there were, however, favourable views about evidence-based management of asthma, such as the use and benefits of an asthma action plan. Among the strategies to improve uptake described by the participants was the use of an innovative format through technology (e.g., a mobile app) and family involvement. The global pandemic has accelerated the use of technology to deliver care [238]. The ability of patients with asthma to self-manage their condition through mobile apps, an option described by participants in this study, has the potential to reduce the burden of chronic illness in cost-constrained healthcare systems [83].

Although there are often assumptions that older adults are resistant to technology, the findings of this study implied otherwise. Several older adults from this study saw the value of using technology such as a mobile app to manage their health. Participants described support networks (such as family) that – if needed – could enable them to use an app and asthma action plans more effectively. A scoping review suggested that older adults might have varying degrees of interest and skills to use technology to self-manage their conditions at home [239]. Understanding older adults’ context during intervention design and careful planning of tailored support are essential to improve adoption of technology-based intervention [239]. Involvement of family members or carers is one such support [239]. Family involvement in interventions is commonly reported in conditions involving children [240] and mental disorders [241] but not with asthma. Although evidence is still lacking of its value in managing people living with chronic illness, family involvement has shown promising results, including improved uptake of self-management tasks and health outcomes [239,242], highlighting the impact family could have in creating favourable illness experiences. In this setting, there are cultural dimensions to family involvement in disease management. For example, the concept of filial piety governs family values and influences household structure in Malaysia [199,200], resulting in a setting that features multigenerational households. In other settings, family involvement may have a less prominent
role, especially where elderly people are less likely to be part of a close family group.

Participants described the lack of provision of asthma action plans from healthcare professionals; thus, understanding the healthcare professionals’ perspectives is crucial to improve the delivery of guideline-recommended asthma care. Quality healthcare is the right of every person; however, providing guideline-recommended care may be challenging, particularly in a low-resource setting. In this study, I did not interview healthcare professionals; however, a qualitative study among Malaysian healthcare professionals in the same setting described doctors’ views about the challenges in providing written asthma action plans to patients [243]. It was reported that healthcare professionals perceived that they needed more training to improve the delivery of asthma self-management education and provide personalised care for patients, particularly those with limited health literacy [243]. In addition, they discussed the limited availability of templates of asthma action plans in clinical practice [243]. They stated that the written format of the asthma action plans used in clinics was not appropriate for meeting the needs of people with limited health literacy [243], highlighting the need for system-level intervention to narrow the gap in health inequality.

7.6 Conclusion and implications for intervention development based on this qualitative study using health literacy framework analysis

In using the health literacy framework analysis, I learned the following:

- Understanding asthma was influenced by social norms, whereas self-management decisions were based on health beliefs and experiential knowledge, highlighting the need for a whole-system intervention to implement evidence-based asthma management.
- Asthma action plans were rarely provided or discussed during asthma follow-up consultations, a gap at the individual level that an intervention could remedy.
• Recommendations to improve awareness, adoption and use of a written asthma action plan were practical and could potentially be used in an intervention to support self-management. The recommendations include use of multilingual health information, pictorial-based asthma action plans, family involvement and the use of digital technology.

7.7 Summary and next step

This chapter described the findings of a framework analysis. The key theme in this analysis is that people living with asthma weigh the health information provided by the health system with their social norms and their culturally determined health practices. The findings were informed by the four domains of Sørensen’s health literacy framework: i) Access; ii) Understand; iii) Appraise; and iv) Apply, in the context of health information. I learned that supporting self-management in this setting needs a whole-system approach that addresses patients, professionals and organisations, with inclusion of societal aspects. However, my findings suggest that asthma action plans were rarely provided and taught during asthma follow-up consultations, a gap that I could seek to fill. In the next chapter, with reference to the 6SQuID model, I use the study findings described in Chapters 5, 6, and 7 to illustrate the mechanism of change systematically.
Chapter 8  Theory of change: mechanism of impact

The previous chapters detailed the results of the systematic review (Chapter 5) and the qualitative study (Chapter 6 and 7). This chapter describes how I utilised these study findings and previous literature to design an intervention underpinned by a theory of change (Step 3 of the 6SQuID model). Figure 37 depicts the work I undertook for the entire PhD programme, which is reported in this thesis using the 6SQuID model (Steps 1 to 4) [107]. The red circle refers to the part of the work discussed in this chapter.

**Figure 37 Using the 6SQuID model as an overall framework for this PhD.**

8.1 Objective of this chapter
To design an intervention underpinned by a theory of change.

8.2 Intervention development was based on the evidence gathered so far
Table 24 outlines the learning points for an intervention development based on the findings from the systematic review (Section 5.4); the qualitative study: narrative analysis (Section 6.4); and the health literacy framework analysis (Section 7.4).
Table 24 Implications for intervention development based on previous projects in this PhD.

<table>
<thead>
<tr>
<th>Projects</th>
<th>Learning points</th>
</tr>
</thead>
<tbody>
<tr>
<td>Systematic review</td>
<td>• The development of intervention requires theoretical soundness, necessitating the use of a framework to inform this development.</td>
</tr>
<tr>
<td></td>
<td>• Based on the Behaviour Change Wheel framework, intervention functions that were not used in included studies represent gaps that could be utilised in future interventions.</td>
</tr>
<tr>
<td></td>
<td>• Involving stakeholders, particularly end-users such as patients, at the intervention development stage could enhance uptake and make the intervention more applicable to solving real-world problems.</td>
</tr>
<tr>
<td>Qualitative study (Narrative analysis)</td>
<td>• The concept of autonomy was the primary lens that participants used to describe their experiences living with asthma.</td>
</tr>
<tr>
<td></td>
<td>• Their challenges are multilevel; thus, intervention to improve people's illness experiences requires a whole-system approach that operates on individual, healthcare professional, organisational and societal levels.</td>
</tr>
<tr>
<td>Qualitative study (Health literacy framework analysis)</td>
<td>• Understanding asthma was influenced by social norms, whereas self-management decisions were based on health beliefs and experiential knowledge, highlighting the importance of a whole-system intervention to impart evidence-based asthma management.</td>
</tr>
<tr>
<td></td>
<td>• The findings suggest that written asthma action plans were rarely provided or discussed during asthma follow-up consultations, a gap at the individual level that an intervention could address.</td>
</tr>
<tr>
<td></td>
<td>• Recommendations to improve awareness, adoption and use of a written asthma action plan were practical and could potentially be used in an intervention to support self-management and improve asthma control.</td>
</tr>
</tbody>
</table>
I used these learning points and previous literature to systematically illustrate the types of interventions and their components that might positively impact asthma control. I demonstrated this aspect in the context of Steps 1–4 of the 6SQuID model. 6SQuID is described in detail in Section 4.2.2, but in summary, it describes six practical steps for how intervention can be developed. These steps are illustrated in Figure 38.

**Figure 38 Descriptions of the six steps of the 6SQuID model.**

- 6SQuID Step 1: Define and understand the problem and its causes
- 6SQuID Step 2: Clarify which causal or contextual factors are malleable and have the greatest scope for change
- 6SQuID Step 3: Identify how to bring about change: the change mechanism
- 6SQuID Step 4: Identify how to deliver the change mechanism
- 6SQuID Step 5: Test and refine on a small scale
- 6SQuID Step 6: Collect sufficient evidence of effectiveness to justify a rigorous evaluation/implementation

Using the six steps of the 6SQuID model, I describe how the steps were applied in the intervention development process (Table 25).

**Table 25 How the 6SQuID model is applied in the intervention development process.**

<table>
<thead>
<tr>
<th>Steps</th>
<th>Overarching objective: To design an intervention underpinned by a theory of change</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Specific question to answer</td>
</tr>
<tr>
<td></td>
<td>What are the causes of poor asthma control in adults with limited health literacy in the primary care setting in Klang?</td>
</tr>
</tbody>
</table>

[Chapter 8: Theory of change] 211
| 2. | Clarify which causal or contextual factors are malleable and have the greatest scope for change | Which cause has the greatest scope to improve asthma control of adults with limited health literacy in the primary care setting in Klang? |
| 3. | Identify how to bring about change: the change mechanism | What is the logic model to improve asthma control among adults with limited health literacy in the primary care setting in Klang? |
| 4. | Identify how to deliver the change mechanism | How should the asthma intervention be delivered to adults with limited health literacy in the primary care setting in Klang? |
| 5. | Test and refine on a small scale | These steps are not within the scope of this PhD. However, see Section 10.4.3 for a description of future work. |
| 6. | Collect sufficient evidence of effectiveness to justify a rigorous evaluation/implementation | |

### 8.2.1 6SQuID Step 1: Understand the problems around the implementation of supported asthma self-management components and their causes

**Question** (Table 25): What are the causes of poor asthma control in adults with limited health literacy in the primary care setting in Klang?

The relationship between limited health literacy and health outcomes such as asthma control is complex, but studies have shown that interventions addressing health literacy needs may improve asthma outcomes [47, 68, 163]. Concerning asthma outcomes, a study conducted in the primary care setting in Klang (details in Section 2.4.3) found that more than half of adults with asthma who have limited health literacy had uncontrolled asthma [1]. Thus, I used this evidence to justify my decision to use asthma control as the outcome of interest and I used this evidence to inform the development of my intervention.

Previous literature has described several causes of poor asthma control from a patient, healthcare professional and system point of view, including limited access to guideline-recommended care, environmental factors, incorrect
diagnosis, co-morbidities, cultural aspects including health beliefs, and smoking [244-246]. These causes are not specific to people with limited health literacy [244-246], however, these studies’ findings reflect the findings of my qualitative study. Among people with asthma, the literature suggests that health literacy affects asthma control through its effect on other variables, particularly knowledge about asthma and its management [57,247]. My qualitative study highlighted several potential causes of poor asthma control among adults with limited health literacy (Table 26) at different levels:

i) Individual
ii) Interpersonal
iii) Organisational
iv) Societal

In the 6SQuID Step 1 exercise, I found that causes at the individual level that may have influenced at the interpersonal, organisational, and societal levels; reflected the previously identified causes of poor asthma control (e.g., limited access to guideline-recommended care, environmental factors, incorrect diagnosis, comorbidities, cultural aspects, including health beliefs, and smoking). The identified causes at the individual level could be clustered under three themes. The themes were derived based on guideline recommendations of supported self-management [5,11,12]:

i) Causes relating to the understanding of asthma and its management;
ii) Causes relating to the lack of attendance for a follow-up consultation;
iii) Causes relating to the lack of ownership of a written asthma action plan.

Next, in Step 2 of the 6SQuID model, I identify potential malleable causes to be included in the intervention.
Table 26 The causes of poor asthma control in adults with limited health literacy in the primary care setting in Klang.

<table>
<thead>
<tr>
<th>Potential causes at different levels</th>
<th>Individual</th>
<th>Interpersonal</th>
<th>Organisational</th>
<th>Societal</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Relating to the understanding of asthma and its management:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Health beliefs influence understanding about asthma</td>
<td>Breakdown in doctor–patient communicatio and relationship</td>
<td>Lack of options for low-literacy tailored asthma information</td>
<td>Social-cultural norms and culturally determined health practices influence self-management decisions.</td>
<td></td>
</tr>
<tr>
<td>• Asthma management is based on previous experience of what works</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Relating to the lack of attendance for a follow-up consultation:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Attendance for follow-up consultation was based on individual perceived needs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Asthma is perceived as unimportant among those with co-morbidities</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Relating to the lack of ownership of a written asthma action plan:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Understanding about asthma: lack of skills to access and appraise accurate information about asthma</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Lack of awareness about self-management strategies and the skill to apply them</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Challenges in using standard written asthma action plans (e.g., they are perceived as too wordy)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Needing support from others to understand and use an asthma action plan</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Footnote: At the individual level, the themes relating to regular follow-up consultation and provision of an asthma action plan coincide with guideline recommendations on the importance of patient education to improve understanding about a health condition and the impact of supported self-management on asthma control [5,11,12].
8.2.2 6SQuID Step 2: Clarify which causal or contextual factors are malleable and have the greatest scope for change

**Question** (Table 25): Which cause has the greatest scope to improve asthma control of adults with limited health literacy in the primary care setting in Klang?

Based on the causes (Table 26), I identified malleable causes for poor asthma control among adults with limited health literacy in this population, as well as identifying supporting evidence for improving asthma control in other interventions or programmes in the literature. I included the findings of my systematic review in this exercise. At the end of this exercise, I reviewed which causes were malleable, had the greatest scope for change, and were feasible for this PhD programme of work.

*Table 27 Mapping of problems and interventions or strategies which could potentially solve the problems.*
### Potential causes of problems with evidence-based self-management at different levels
(From perspectives of people with asthma)

<table>
<thead>
<tr>
<th>Individual</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Causes relating to the understanding of asthma and its management:</strong></td>
</tr>
<tr>
<td>• Health beliefs influence understanding about asthma</td>
</tr>
<tr>
<td>• Asthma management is based on previous experience of what works</td>
</tr>
<tr>
<td><strong>Causes relating to the lack of attendance for a follow-up consultation:</strong></td>
</tr>
<tr>
<td>• Attendance for follow-up consultation was based on individual perceived needs</td>
</tr>
<tr>
<td>• Asthma is perceived as unimportant among those with co-morbidities</td>
</tr>
<tr>
<td><strong>Causes relating to the lack of ownership of a written asthma action plan:</strong></td>
</tr>
<tr>
<td>• Understanding about asthma: lack of skills to access and appraise accurate information about asthma</td>
</tr>
<tr>
<td>• Lack of awareness about self-management strategies and the skill to apply them</td>
</tr>
<tr>
<td>• Challenges in using standard written asthma action plans (e.g., they are perceived as too wordy)</td>
</tr>
<tr>
<td>• Needing support from others to understand and use an asthma action plan</td>
</tr>
</tbody>
</table>

### Could other interventions be implemented?
(Evidence from this PhD’s findings and previous literature)

- My systematic review findings (Section 5.4) did not provide evidence on health outcomes from all the included studies [142].
- Improved understanding of evidence-based health information is likely when tailored and is linked to better health outcomes [53,58,87,208,248].
- Reviews suggest self-management interventions for people with limited health literacy may improve health outcomes [86,87].
- There was a lack of health literacy-based interventional studies that measured asthma-related health beliefs and experiential knowledge leading to health outcomes.

### Are the causes malleable, and how great is their scope for change in an intervention?

- Yes, the causes are malleable.
- Regarding causes relating to lack of understanding about asthma and self-management, there is evidence that evidence-based health information is an essential (but not sufficient) component for improving health outcomes [17].
- There is evidence to support multi-component interventions to improve health outcomes [87,210].
- Developing an intervention to improve understanding of asthma is within the scope of my PhD.
| Interpersonal | • Breakdown in doctor–patient communication and relationship (e.g., language and medical jargon) | • Reviews provide broadly consistent evidence that doctor–patient communication and relationship modification improved understanding of health information and advice among people with limited health literacy [58]. These improvements are linked to better health outcomes [53,58,87,208,248] | • Yes, there is evidence suggesting that health literacy-based interventions focusing on healthcare professionals’ communication and partnership could improve asthma control.  
• However, as part of HEAL Asthma, (the broader RESPIRE programme of work in Malaysia) an intervention to enhance the delivery of care among healthcare professionals is underway. This is thus beyond the scope of this PhD which focusses specifically on the needs of people with limited health literacy. |
| --- | --- | --- | --- |
| Organisational | • Lack of options for low-literacy tailored health information | • Low-literacy health information and picture-based asthma action plans facilitate healthcare professionals to tailor their asthma recommendations and improve communications [249]. Improved communication and understanding of health information is linked to better health outcomes [53,58,87,208,248]. | • Yes, there is evidence that providing low-literacy tailored health information improves understanding of disease and its management and is linked to health outcomes [53,87,208,248].  
• A focus on delivering low literacy information is within scope for my PhD. This is within the context of the pictorial action plans being used in the broader HEAL asthma work. |
<table>
<thead>
<tr>
<th>Societal</th>
</tr>
</thead>
</table>
| - Social-cultural norms and culturally determined health practices influence self-management decisions.
| - Stigma: Lack of support and understanding from society (including family) about asthma needs.
| - My systematic review (Section 5.4) found that although cross-cultural elements were addressed in asthma interventions, their impact on health outcomes is unclear [142].
| - There was a lack of community-based intervention to measure the impact of socio-culture elements and stigma on health outcomes.
| - Malleable at societal level and likely over a long time period.
| - Upstream intervention will be required, e.g., policy to support societal restructuring or environmental change [250].
| - This PhD programme of work highlighted the need to focus on societal support and strategies to improve asthma care delivery. This is the area for potential future work to improve asthma care in Malaysia, particularly among people with limited health literacy who tend to be socioeconomically vulnerable and disproportionately affected by social inequalities. |
Causes of poor asthma control are interrelated and complex; thus, targeting multiple components could yield a better outcome than targeting a single cause [210,248]. Apart from considering the malleable causes at the individual level, I adapted the causes at interpersonal, organisational and, (to a certain extent) societal level for the intervention development. For example, although there is no definite evidence of improved health outcomes due to a change of societal environment, developing an asthma-friendly environment (within a family, for example) could raise awareness and reduce stigma, all of which are important factors to consider. Thus, in Step 2, I identified potential malleable causes to be included in the intervention:

i) Causes relating to lack of understanding about asthma and self-management;

ii) Causes relating to the lack of attendance for a follow-up consultation;

iii) Causes relating to the lack of ownership of a written asthma action plan;

iv) Breakdown of doctor–patient communication and relationship;

v) Lack of options for low-literacy tailored health information;

vi) Societal causes (to a limited extent):
   a) Social-cultural norms and culturally determined health practices influence self-management decisions;
   b) Stigma: lack of support and understanding from society (including family) about asthma needs.

Next, in Step 3 of the 6SQuID model, I elaborate on how to bring the multiple components together in an intervention.

8.2.3 6SQuID Step 3: Identify how to bring about change: the change mechanism

**Question** (Table 25): What is the logic model to improve asthma control among adults with limited health literacy in the primary care setting in Klang?

The objective of the intervention is to improve asthma control among adults with limited health literacy. To achieve this objective, I constructed a logic model to visualise the change mechanism, informed by Table 27. A logic model offered a systematic and visual way to present and share an understanding of
the causal pathway, which would identify the components of the intervention, how it would work, and the changes or results I hoped to achieve [251]. The logic model uses images, words and diagrams to describe the sequence of activities thought to bring about change and how these activities are linked to the potential outcomes [251]. It allows stakeholders to visualise the roadmap describing events that connect the planned intervention and the desired outcomes [251].

**Steps to construct the logic model**

i) In the first column of the logic model, I grouped the causes for poor asthma control among adults with limited health literacy (Figure 39).

![Figure 39 The initial step in constructing the logic model.](image)

ii) Based on this list, I mapped out how problems could be overcome in three aspects [137]: a. C – capacity (knowledge), b. O – opportunity (social) and c. M – motivation. The second column of the logic model illustrates this process Figure 39.
iii) Based on this initial mapping, I refined the process and matched the causes to intervention components that could potentially solve the problem using the BCW framework (Table 28). The solutions that could potentially initiate a behaviour change were based on findings, participants’ recommendations from the qualitative study, and the literature. I replicated the mapping exercise I undertook when conducting the systematic review (Section 5.4.5) [142].

iv) I then mapped the components of an intervention that could potentially provide the solutions. From the systematic review findings, there were some gaps in intervention functions that could be used. To recapitulate, the green boxes in Table 29 showed how the COM-B components were linked to the intervention functions, and the components of behaviour can be linked to the interventions in more than one way. For example, physical capability (e.g., skills) can be achieved through training and/or enabling interventions. The blue boxes (Table 30) indicate intervention functions used in the studies included in the systematic review (Chapter 5). The grey boxes (Table 30) indicate the intervention functions not used previously that could potentially be incorporated in a future intervention to support self-management aimed at people with limited health literacy.

As an alternative to the standard written asthma action plan, I planned to use a pictorial asthma action plan to overcome challenges in understanding and using a written asthma action plan. This decision was supported by the promising outcomes of the pictorial asthma action plan from the systematic review work I conducted earlier [116,140,142]. In addition, pictograms may improve doctor–patient communications [249]. As described in Section 2.1.3, there is an existing resource for a culturally tailored pictorial asthma action plan, deriving from RESPIRE’s HEAL Asthma work, which I could use. There were two reasons why I chose to use this pictorial asthma action plan:
### Table 28 Mapping of problem, causes and intervention components.

<table>
<thead>
<tr>
<th>Causes</th>
<th>Intervention component which could potentially address the cause</th>
<th>Mapping in matrix [138] 1. COM-B 2. Intervention function</th>
<th>Explanation (based on Behaviour Change Wheel taxonomy) [138].</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Relating to the understanding of asthma and its management</td>
<td>Signposting of sources of information about asthma and its management (text and videos)</td>
<td>1. COM-B Capability: Psychological</td>
<td>The capacity to engage in the necessary thought process</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Intervention function: Education</td>
<td>Increasing knowledge and understanding</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1. COM-B Motivation: Reflective</td>
<td>Reflective processes involving evaluations and plans</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Intervention function: Persuasion</td>
<td>Using any form of communication to induce positive feelings or stimulate action</td>
</tr>
<tr>
<td>• Relating to the lack of attendance for a follow-up consultation</td>
<td>Using technology to support behaviour change</td>
<td>1. COM-B Opportunity: Physical</td>
<td>Physical opportunity implies an opportunity afforded by the environment. Physical opportunity, in this case, relates to the object or technology that interacts with individuals through prompts in order to influence behaviour.</td>
</tr>
<tr>
<td>• Relating to the lack of ownership of a written asthma action plan</td>
<td></td>
<td>2. Intervention function: Environmental restructuring</td>
<td>Environmental restructuring implies changing the physical context of the environment. Environmental restructuring in this context refers to item 12.5: Adding object (e.g., technology) to the environment, where the technology is added to facilitate the performance of a behaviour.</td>
</tr>
<tr>
<td>• Relating to the lack of ownership of a written asthma action plan</td>
<td>1. COM-B Motivation: Automatic</td>
<td>Automatic processes involving emotions and impulses that arise from associative learning and/or innate dispositions</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>• Lack of options for low-literacy tailored asthma information</td>
<td>2. Intervention function: Persuasion</td>
<td>Using any form of communication to induce positive feelings or stimulate action</td>
<td></td>
</tr>
<tr>
<td>A pictorial asthma action plan</td>
<td>1. COM-B Capability: Psychological</td>
<td>The capacity to engage in the necessary thought process</td>
<td></td>
</tr>
<tr>
<td>• Relating to the lack of ownership of written asthma action plan</td>
<td>2. Intervention function: Enablement</td>
<td>Increasing means and reducing barriers Enablement in this context refers to item 1.4: Action-planning of the Behaviour Change taxonomy, where a detailed plan for carrying out certain actions is provided.</td>
<td></td>
</tr>
<tr>
<td>Education about a pictorial asthma action plan</td>
<td>1. COM-B Capability: Psychological</td>
<td>The capacity to engage in the necessary thought process</td>
<td></td>
</tr>
<tr>
<td>• Breakdown in doctor–patient communication and relationship</td>
<td>2. Intervention function: Education</td>
<td>Increasing knowledge and understanding</td>
<td></td>
</tr>
<tr>
<td>Issue</td>
<td>Action/Intervention</td>
<td>Function</td>
<td>Description</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------</td>
<td>----------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Relating to the lack of ownership of written asthma action plan</td>
<td>Training to use a pictorial asthma action plan</td>
<td>1. COM-B Capability: Physical</td>
<td>The capacity to carry out a particular physical skill</td>
</tr>
<tr>
<td>Breakdown in doctor–patient communication and relationship</td>
<td></td>
<td>2. Intervention function: Training</td>
<td>Imparting skills</td>
</tr>
<tr>
<td>Social-cultural norms and culturally determined health practices influence self-management decisions.</td>
<td>Family involvement (through family-based intervention training)</td>
<td>1. COM-B Opportunity: Social</td>
<td>The opportunity provided by the cultural milieu influences how a person thinks and, as a result, behaves. In this context, social opportunity relates to the networks and relationships (e.g., family), which people draw upon in identifying and carrying out a possible course of action.</td>
</tr>
<tr>
<td>Stigma: lack of support and understanding from society (including family) about asthma needs</td>
<td></td>
<td>2. Intervention function: Enablement</td>
<td>Increasing means and reducing barriers</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Enablement in this context refers to item 3.2: Social support (practical), where family members advise on, arrange or provide help for the performance of specific behaviour.</td>
</tr>
</tbody>
</table>

Footnote: Individual level; Interpersonal level; Organisational level; Societal level
i) the preliminary findings from HEAL Asthma’s feasibility study of the paper-based pictorial asthma action plan showed promising results on health outcomes, and

ii) participants in my qualitative study recommended use of images as an alternative to a written asthma action plan.

I acknowledged that changing the social environment would not be feasible within this PhD; however, involving key family members in an intervention may provide support within individuals’ social environment. Thus, I included family-based training as part of the intervention component, to support asthma self-management intervention (Table 28). Next, I addressed the accessibility of accurate health information through signposting to reliable information about asthma and evidence-based self-management practices.

v) Finally, based on the recommendations from the health literacy framework analysis, Section 7.4.2, I looked for and chose a method which is practical in day-to-day living, that could potentially deliver the components listed to provide solutions to the identified problems. I will be elaborate on these in Step 4.
### Table 29: For comparison: The original matrix of core components of behaviour (COM-B) and the intervention functions.

<table>
<thead>
<tr>
<th>Core components of behaviour, the COM-B model</th>
<th>Intervention functions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Education</td>
</tr>
<tr>
<td>Capability</td>
<td></td>
</tr>
<tr>
<td>physical</td>
<td>✓</td>
</tr>
<tr>
<td>psychological</td>
<td>✓</td>
</tr>
<tr>
<td>Opportunity</td>
<td></td>
</tr>
<tr>
<td>physical</td>
<td>✓</td>
</tr>
<tr>
<td>social</td>
<td>✓</td>
</tr>
<tr>
<td>Motivation</td>
<td></td>
</tr>
<tr>
<td>automatic</td>
<td>✓</td>
</tr>
<tr>
<td>reflective</td>
<td>✓</td>
</tr>
</tbody>
</table>

Footnote: In the original matrix proposed by Michie et al., the green boxes showed how the COM-B components were linked to the intervention functions [138].

### Table 30: How the adapted matrix was employed in this PhD programme of work.

<table>
<thead>
<tr>
<th>Core components of behaviour, the COM-B model</th>
<th>Intervention functions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Education</td>
</tr>
<tr>
<td>Capability</td>
<td></td>
</tr>
<tr>
<td>physical</td>
<td>✓</td>
</tr>
<tr>
<td>psychological</td>
<td>✓</td>
</tr>
<tr>
<td>Opportunity</td>
<td></td>
</tr>
<tr>
<td>physical</td>
<td>✓</td>
</tr>
<tr>
<td>social</td>
<td>✓</td>
</tr>
<tr>
<td>Motivation</td>
<td></td>
</tr>
<tr>
<td>automatic</td>
<td>✓</td>
</tr>
<tr>
<td>reflective</td>
<td>✓</td>
</tr>
</tbody>
</table>

Footnote: The blue boxes indicate the components being used and the grey boxes the components not being used by the included interventions in my systematic review. ✓ indicates the functions used by the components of the intervention I developed.
I finally completed the logic model (Figure 40) to understand the causes, the potential solutions and the potential benefits.

**Figure 40 The completed logic model demonstrates how the multiple components are brought together in a single intervention.**

Next, in Step 4 of the 6SQuID model, I identify how the intervention (and its components) could be delivered.

**8.2.4 6SQuID Step 4: Identify how to deliver the change mechanism**

**Question** (Table 25): How should the asthma intervention be delivered to adults with limited health literacy in the primary care setting in Klang?

In Step 3 of the 6SQuID model exercise, the components of the proposed asthma self-management intervention aimed at people with limited health literacy were defined. These included providing tailored information (based on an existing pictorial asthma action plan), using technology to support
behaviour change, family involvement, and signposting to reliable sources of information.

There were various ways these components could be delivered. The systematic review (Chapter 5) highlighted that the included studies delivered components (problem solving skills [115], evidence-based knowledge about asthma [117,139] and asthma action plans [116,140]) through face-to-face education sessions [115], paper-based information [116,140] and video-based information [117,139]. However, none of the included studies in this systematic review described the use of a mobile app. Table 31 summarises the mapping of the delivery formats used in the studies included in the systematic review and the potential components of my intervention. These components were identified based on the recommendations of the participants in my qualitative study. The ‘check’ symbol in Table 31 indicates whether the delivery format could potentially deliver the components of my intervention.

**Table 31 Summary of potential delivery options for the intervention components and justification for use.**

<table>
<thead>
<tr>
<th>Delivery format</th>
<th>The potential components of the intervention</th>
<th>Justification</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pictorial asthma action plan</td>
<td>Technology to support behaviour change</td>
</tr>
</tbody>
</table>
| Paper           | ✓ | x | ✓ | ✓ | • A paper-based option cannot accommodate technology to support behaviour change.  
• Listing sources of health information on paper may still require people to use other platforms to search for it. |
<table>
<thead>
<tr>
<th></th>
<th>✓</th>
<th>✓</th>
<th>✓</th>
<th>✓</th>
<th></th>
</tr>
</thead>
</table>
| Video    | ✓  | ✓  | ✓  | ✓  | • A video-based option can potentially deliver and support these components.  
• However, people may need devices to play and motivation to open the videos; thus, videos may not be very effective in supporting behaviour change.  
• Listing sources of health information on the video may still require people to use other platforms to search for it. |
| Web-based| ✓  | ✓  | ✓  | ✓  | • A web-based option can potentially deliver and support these components.  
• However, people may need devices such as computers to access the web-based intervention.  
• The intervention could be developed to be mobile-friendly, but this could be costly in development and would require an internet connection to use. |
Mobile application (app) ✓ ✓ ✓ ✓ ✓

- The mobile app option could potentially deliver and support these components.
- Mobile phones are considered everyday devices that people use.
- However, apps are only supported by smartphones.
- Once the intervention app is installed in a smartphone, to a certain extent, some of the functions can be developed to be usable without an internet connection (using features installed in the smartphone memory).
- An app provides quick access and delivers reminders to support behaviour change (e.g., adherence).

Although the face-to-face format of intervention delivery was reported in one of the studies included in the systematic review [142], I did not consider this option for delivering the potential components of my intervention. Such a delivery method is potentially labour intensive and will require substantial training to ensure uniformity of intervention delivery; a challenging method to implement in a low-resource setting of primary care in Malaysia. Based on the logic model (Figure 40), I propose using a mobile app to deliver the intervention components based on the recommendations made by participants in Chapter 7. Mobile technology such as an app may potentially overcome the dependency on healthcare professionals to access asthma action plans, empowering patients through ownership and use of a device they use daily. The mobile app may provide a physical opportunity (Table 28) to support asthma self-management through providing health information tailored to health literacy needs. Mobile technology has the potential to support asthma self-management [252,253]. Use of apps have been shown to boost confidence during the early stages of asthma treatment when patients learn to
accept, understand and control their condition [252]. Regarding the effect of mobile-based interventions on health literacy, a systematic review found a limited number of studies examining this but the review highlighted that seeking and evaluating health information improved after the use of a mobile-based intervention [254]. However, none of the included studies looked at a population with asthma [254].

**In summary**, using technology and devices that people are familiar with, such as a mobile app, to deliver intervention components could be beneficial. Further development of mobile-based intervention aimed at people with limited health literacy to support their condition, particularly asthma, is needed; thus, this programme of work is essential to bridge the gap in the literature.

### 8.2.5 6SQuID Steps 5 and 6

Step 5 emphasises testing and refining on a small scale, and Step 6 elaborates on collecting sufficient evidence of effectiveness to justify a rigorous evaluation or implementation. These steps are not within the scope of this PhD. However, reflecting the recommendation of Steps 5 and 6 of the 6SQuID model, I describe, in Section 10.4.3, future work to follow-on from this PhD programme of work.

### 8.3 Conclusion and implications for intervention development based on the 6SQuID model exercise

By using the 6SQuID model, I learned the following:

- In Step 1 of the 6SQuID model exercise, the causes of poor asthma control among people with limited health literacy are multilevel:
  - Individual
  - Interpersonal
  - Organisational
  - Societal
I identified the underlying causes from the qualitative study in (Sections 6.4 and 7.4) that highlighted multilevel causes, relating to individuals, healthcare professionals and organisations, and including the societal level. Targeting these equally important levels for intervention development has the potential to improve the illness experiences of people with asthma. Thus, in step 2, I identified potential malleable causes to be included in the intervention and became my focus for change in Step 3 of the 6SQuID model exercise:

i) Causes relating to lack of understanding about asthma and self-management
ii) Causes relating to the lack of attendance for a follow-up consultation.
iii) Causes relating to the lack of ownership of written asthma action plan.
iv) Breakdown in doctor-patient communication and relationship.
v) Lack of options for low-literacy tailored health information.
vi) Societal causes (to a limited extent)
   o Social-cultural norms and culturally determined health practices influence self-management decisions.
   o Stigma: Lack of support and understanding from society (including family) about asthma needs.

Using COM-B of the BCW framework in my logic model (Step 3), the components of the proposed asthma self-management intervention aimed at people with limited health literacy included providing tailored information (a pictorial asthma action plan), the use of technology to support behaviour change, family involvement, and signposting to reliable sources of information.

Delivery of intervention (Step 4) using the type of technology and devices familiar to people, such as a mobile app, can potentially deliver these intervention components effectively.
8.4 Summary and next step

In this chapter, I have used the 6SQuID model to describe the decisions underpinning the design and development of the intervention based on findings of the systematic review and qualitative study. I concluded Step 4 of the 6SQuID model by proposing an asthma self-management mobile app aimed at people with limited health literacy. However, I also recognised the need to support other aspects of behaviour change related to evidence-based asthma self-management practices. To do this, I planned and carried out an intervention design workshop using a Design Sprint method that involves all stakeholders [108,255]. The next chapter describes the conduct and findings of the Design Sprint workshop.
Chapter 9  The Design Sprint method: developing and testing of an asthma self-management mobile app aimed at people with limited health literacy

In the previous chapter, I discussed the use of the 6SQuID model to inform my intervention development using the findings of previous literature, the systematic review and qualitative study (Chapters 5, 6 and 7). This chapter reports the review of two digital technology development frameworks, before describing the conduct and outcomes of the Design Sprint method to develop and refine an intervention. Figure 41 depicts the projects I undertook for the PhD programme of work, which is reported in this thesis using the 6SQuID model (Steps 1 to 4) [107]. The red circle refers to the part of the work that I discuss in this chapter.

*Figure 41 Using the 6SQuID model as an overall framework for this PhD.*
Table 32 outlines the publication related to the Design Sprint method. This chapter uses the initials of the co-authors to describe their contributions in the PhD programme of work. In addition, the technologists were: Aidil Goh (AG) and Marzuqi Mohamed (MM).

**Table 32 Summary of the publication and the list of co-authors.**

| The Design Sprint workshop was published in the Journal of Medical Internet Research (Appendix 21) |
| Salim H (HS), Lee PY (PYL), Shariff-Ghazali S (SSG), Cheong AT (ATC), Wong J (JW), Young I (IY), Pinnock H (HP) on behalf of the RESPIRE Collaboration. Developing an asthma self-management intervention through a web-based design workshop for people with limited health literacy: User-centered design approach. J Med Internet Res. 2021;23(9): e26434 |

9.1 **Introduction**

The asthma self-management intervention will be delivered following GINA recommendations [5] and incorporate a pictorial asthma action plan delivered using a mobile app. Various studies have shown that extensive use of pictograms, images, interactive functions, and prompts appeals to people with asthma and may improve understanding of information in mobile apps [81,256-258]. To date, Malaysia’s health-based apps do not fall under the Malaysian Medical Device Act 2012 (Act 737) or Medical Device Regulations 2012 [259]. The app developed in this study will therefore not need to go through any legislative process in Malaysia [259].

In Table 33, I present the learning points from previous projects within this PhD programme of work, updated from Table 24 to include the learning points from the Theory of Change chapter. These learning points helped to inform my intervention design work.
### Table 33 Implications for intervention development from the previous projects.

<table>
<thead>
<tr>
<th>Projects</th>
<th>Learning points</th>
</tr>
</thead>
<tbody>
<tr>
<td>Systematic review</td>
<td>• The development of intervention may require theoretical soundness, necessitating the usage of a framework to inform its development.</td>
</tr>
<tr>
<td></td>
<td>• Based on the Behaviour Change Wheel framework, intervention functions that were not used in included studies represent gaps that could be utilised in future interventions.</td>
</tr>
<tr>
<td></td>
<td>• Involving stakeholders, particularly end-users such as patients, at the intervention development stage could enhance uptake and make the intervention more applicable to solving real-world problems.</td>
</tr>
<tr>
<td>Qualitative study (Narrative analysis)</td>
<td>• The concept of autonomy was the primary lens that participants used to describe their experiences living with asthma.</td>
</tr>
<tr>
<td></td>
<td>• Their challenges are multilevel; thus, intervention to improve people’s illness experiences requires a whole-system approach.</td>
</tr>
<tr>
<td>Qualitative study (Health literacy framework analysis)</td>
<td>• Understanding asthma was influenced by social norms, whereas self-management decisions were based on health beliefs and experiential knowledge, highlighting the importance of a whole-system intervention to impart evidence-based asthma management.</td>
</tr>
<tr>
<td></td>
<td>• The findings suggest that written asthma action plans were rarely provided or discussed during asthma follow-up consultations, a gap at the individual level that an intervention could address.</td>
</tr>
<tr>
<td></td>
<td>• Recommendations to improve awareness, adoption and use of a written asthma action plan were practical and could potentially be used in an intervention to support self-management and improve asthma control.</td>
</tr>
</tbody>
</table>
| Theory of Change: mechanism of impact. | • In Step 1 of the 6SQuID model exercise, the causes of poor asthma control among people with limited health literacy were multilevel.  
• Targeting these equally important levels for intervention development has the potential to improve the illness experiences of people with asthma. Thus, in step 2, I identified potential malleable causes to be included in the intervention and became my focus for change in Step 3 of the 6SQuID model exercise.  
• Using COM-B of the Behaviour Change Wheel framework in my logic model (Step 3), the components of the proposed asthma self-management intervention aimed at people with limited health literacy include providing tailored information (a pictorial asthma action plan), the use of technology to support behaviour change, family involvement, and signposting to reliable sources of information.  
• Delivery of intervention using the type of technology and devices familiar to people, such as a mobile app, can potentially deliver these intervention components effectively. |

### 9.2 Framework for app development

**Oxford App Development Roadmap**

I considered the Oxford App Development Roadmap [260]. The roadmap suggests key aspects to consider before committing to app development. There are six stages in the roadmap [260]: 1) pre-development, 2) design and development, 3) user testing, 4) stakeholder review/clinical validation, 5) medical device process, and 6) external deployment.
Figure 42 Oxford App Development Roadmap by the Academic Health Science Network.

- **Pre-development**: In this stage, developers should consider whether the app is commercially viable (Figure 42). Assessment to ensure viability includes, for example, needs assessment (e.g., why develop a mobile app?) and business justification case (e.g., what is the ongoing support and cost?).

- **Design and development**: Key technical considerations include coding generation, user interface design, system interoperability and capability. As suggested by the Oxford roadmap, this is an iterative process before the refining stage. The app developer then designs a prototype to be used in Stage 3.

- **User testing**: In this stage, the prototype is tested, and findings from Stage 3 allow refinement of the prototype. The user testing stage may take several iterative cycles.

- **Stakeholder review**: The final app should be thoroughly reviewed by key stakeholders within (and perhaps outside) the organisation. The scope of the review(s) will be determined by the medical app’s functionality and intended use. In clinical research, this is the stage where clinical effectiveness is assessed.
• **Medical device process:** Software, including an app, used for diagnostic and therapeutic purposes is considered a medical device under the Medical Device Directive and is subjected to a rigorous conformity assessment, including registration and safety evaluation. Such a process is necessary if the prototype app is developed for commercial use and distribution.

• **External deployment:** In this stage, app developers may need to consider several deployment strategies, including promoting and advertising prototypes on relevant platforms (e.g., the Google Play store) to launch them.

**Design Sprint method**

I considered the Design Sprint method to develop and refine the app in small-scale testing. A Design Sprint method is an emerging, agile and efficient method for developing a technological prototype, including for health research [255,261]. The process was initially designed in the technology sector by Google Ventures for business start-up teams [108]. Involvement of the target population and early testing enhances intervention effectiveness and increases the likelihood of adoption at the implementation stage [262]. The Design Sprint patient-centred or user-centred method consists of five stages, conducted over five days, as described below [108] (Figure 43):
• **Stage 1 – Understanding and mapping problems:** The team comes together in the first stage to understand the long-term aim and expected outcome of the Design Sprint method. The team will describe the problem in partnership with end-users by mapping end-user experiences, to identify difficulties and opportunities to solve them.

• **Stage 2 – Sketching of solutions:** The work now focuses on developing solutions to the target problem, and the sketching process aids in the development of these solutions in a structured and efficient manner.

• **Stage 3 – Deciding on solutions to problems:** The team moves on to determine which solution will be developed into a prototype at this point.

• **Stage 4 – Developing a prototype:** The team then transforms the solutions from Stage 3 into a realistic-looking and working prototype. When tested with users, the design should, at the very least, be of sufficient quality to provide relevant input.

• **Stage 5 – Testing a prototype:** Finally, the prototype is tested to validate the solutions.

Both frameworks, the Oxford App Development Roadmap and the Design Sprint method, describe users’ involvement and use an iterative approach in which the prototype is revised with feedback by end-users. However, neither
framework include feasibility testing and clinical effectiveness trial of a
developed prototype. Nevertheless, due to its rapid development (a five-stage-
over-five-day approach) and incorporation of a testing stage (Stage 5), which
minimises time and cost [262], the Design Sprint method is ideal for a low-
resource setting. I initially planned to use a face-to-face format for the Design
Sprint workshop in March 2021. However, the COVID-19 pandemic and social
distancing requirements meant that I had to adapt to an online workshop
format and lead this workshop remotely from Edinburgh. Furthermore, owing
to its advantages, including its rapid development timeline, the Design Sprint
method was easily adaptable into an online format, with support from the
technologists (see Table 34 for adaptations to the online format).

Using the Design Sprint method, I sought to optimise user experience in the
asthma app development by integrating patients into the design process
[108,262]. It is essential to involve users early in the design stage, as some of
the unique features that people desire can be time-consuming and costly to
build, and a balance may need to be found between desired features [255] and
those with evidence-based recommendations [5,11]. Therefore, I adapted the
five-day Design Sprint method by including utility and usability testing, to
ascertain information that could rapidly and cost-effectively improve the design
[262].

9.3 Study objectives

To develop and refine an asthma self-management app prototype tailored to
the needs of people with limited health literacy:

a. to optimise user experience in prototype development by integrating
   patients and health professionals in the process,

b. to model key aspects of the prototype and test to identify utility and
   usability issues, and

c. to refine and develop the prototype app.
9.4 Methodology

The workshop received ethics approval from the Medical Research and Ethics Committee of the Ministry of Health, Malaysia (ID: NMRR-19-3609-52292) and sponsorship approval by the Academic and Clinical Central Office for Research and Development (ACCORD) at the University of Edinburgh (ID: AC20011). Informed consent was received from all participants before the workshop (see Appendix 22 for PIS and consent form).

9.4.1 Study design

I conducted a five-day online Design Sprint workshop, including qualitative testing of the prototype. I adapted the five-day Design Sprint method as a roadmap to develop the intervention and constructed the workshop in five stages [112] (Figure 43).

Stakeholder (patient and healthcare professional) discussions provided insights into self-management issues in Stage 1, which informed mobile app development in Stages 2 to 4. In Stage 5, I recruited patients with asthma and limited health literacy to test the low-fidelity prototype and give feedback through qualitative interviews. A low-fidelity prototype is a modelled prototype with limited technical functionality [263] that is quick to create and can be easily improved in the light of feedback in the testing stages. The details of each stage are explained in Table 34.

However, due to the COVID-19 pandemic, I had to adapt the workshop’s study design to an online format. The online workshop discussions were conducted on a web-conference platform, Microsoft (MS) Teams, and brainstorming of the idea was conducted on an online board, Miro. While conducting the exercise on Miro, the workshop participants remained connected in MS Teams to allow ongoing discussion. The Miro online board was superseded by a prototype development site, Figma, in Stages 4 and 5, while discussions remained on MS Teams. Two weeks before the workshop, with assistance from the technologists, I contacted each participant (patients and healthcare professionals) to assess technical skills, such as the ability to log on and use
a meeting platform, and logistic issues, such as the quality of the internet connection. The technologist, with whom I worked closely throughout the development process, supported the information technology activities, including the app development. We met once a fortnight to discuss app development progress and challenges.

*Table 34 Process, outcomes and online adaptations of the workshop.*
<table>
<thead>
<tr>
<th>Stages</th>
<th>Stakeholders</th>
<th>Adaptations for online delivery of the workshop</th>
</tr>
</thead>
</table>
| UNDERSTANDING AND MAPPING OF PROBLEMS      | 1. Researchers  
2. Patients  
3. Healthcare professionals  
4. Technologists | 1. Through a web-conference site, Microsoft (MS) Teams, I led a discussion with the whole group (all the stakeholders mentioned) to brainstorm on the long-term goal for the app and the workshop’s aim.  
2. In a separate browser, using an online board, Miro, and assisted by the technologists, I gathered the problems, potential solutions, and mapping of the target where the solutions could occur from the stakeholders’ discussion. The group discussions were audio-recorded during the workshop.  
3. At this stage, I included scientific literature and previous studies (the systematic review and qualitative study) as ‘expert’ input. |
| Objectives:                                |                      |                                                                                                                                 |
| 1. to identify the objectives of the prototype and the workshop; |                      |                                                                                                                                 |
| 2. to map out problems, from healthcare professionals and patients’ perspectives, which technology could help to solve. |                      |                                                                                                                                 |
| SKETCHING OF SOLUTIONS                     | 1. Researchers  
2. Technologists | 1. The researchers and I individually compiled potential solutions to the problems identified in Stage 1 on Miro based on the literature and commercially available health-based apps. The technologist moderated this activity.  
2. Using these compiled solutions, the researchers and I used colourful sticky notes and marker pens to draw rough sketches of our versions of potential solutions. The sketches of the solutions were drawn according to how we wanted these to appear on an app. We took photographs of these sketches and uploaded them to Miro.  
3. We then presented these sketches on MS Teams and discussed the strengths and limitations of each sketch.  
4. The researcher and I were then given three virtual blue dots for voting, and we placed dots on the best sketch. |
<p>| Objective:                                  |                      |                                                                                                                                 |
| 1. to understand a broad range of problems and solutions concerning asthma-self-management. |                      |                                                                                                                                 |</p>
<table>
<thead>
<tr>
<th>Stage 3</th>
<th>DECIDE ON SOLUTIONS TO PROBLEMS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Objective:</td>
<td></td>
</tr>
<tr>
<td>1. to decide on solutions that answered our long-term objectives.</td>
<td></td>
</tr>
<tr>
<td>1. Researchers</td>
<td></td>
</tr>
<tr>
<td>2. Technologists</td>
<td></td>
</tr>
<tr>
<td>1. The most voted sketches were put together, and we had another round of voting on Miro, in which each researcher was given a pink dot, and I was given three purple dots (indicating deciding votes).</td>
<td></td>
</tr>
<tr>
<td>2. The winning sketches were put together to form a storyboard through discussions on Miro and MS Teams. A refined version of the storyboard, using text and visuals, was then constructed by the technologist.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Stage 4</th>
<th>DEVELOPING A PROTOTYPE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Objective:</td>
<td></td>
</tr>
<tr>
<td>1. to build ideas for a low-fidelity prototype.</td>
<td></td>
</tr>
<tr>
<td>1. Researchers</td>
<td></td>
</tr>
<tr>
<td>2. Technologists</td>
<td></td>
</tr>
<tr>
<td>1. On Figma, a prototype development site, the low-fidelity prototype was developed by the technologist, based on the refined version of the storyboard constructed at the end of Stage 3.</td>
<td></td>
</tr>
<tr>
<td>2. While the prototype was being developed, I assigned every researcher a task (e.g., content check or language check) within Figma.</td>
<td></td>
</tr>
<tr>
<td>3. I then led the brainstorming session to develop prompts for the testing day on Google sheets among the researchers.</td>
<td></td>
</tr>
<tr>
<td>4. A Google sheet was created to be used as a virtual fieldnote taking platform during the interviews in Stage 5, at which the researchers would be present as observers. I created a different column for each observer to capture the patient’s evaluation of the prototype simultaneously. The fieldnote was created as a single file, to facilitate comparison and discussion after each interview.</td>
<td></td>
</tr>
</tbody>
</table>
### TESTING A LOW-FIDELITY PROTOTYPE

**Objective:**
1. to validate the solutions for the patients using a qualitative method.

<table>
<thead>
<tr>
<th>1. Researchers</th>
<th>2. Patients</th>
<th>3. Technologists</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I conducted all the interviews through MS teams, with one participant at a time, observed by other researchers (whose video and audio functions were turned off).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. The participant and I could see each other for an ice-breaking session at the start of the testing session. This session was essential to create rapport and to ensure the patient’s readiness, mentally and technically.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Each patient was then given a link to the prototype so that they could browse through it, and they gave comments and answered prompted questions. The patient’s screen was shared within MS Teams.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. The observers synchronously collected the patients’ replies on the utility and usability prompts about the prototype during the interview on a virtual fieldnote.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. I had access to the virtual fieldnote and was able to pick up any point which needed further clarification.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. The interviews were audio-recorded, and browsing activities were video-recorded with the participant’s permission.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

---

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9.4.2 Setting

The workshop, which took place between 22\textsuperscript{nd} and 26\textsuperscript{th} June 2020, was conducted through a secured online meeting platform using a virtual whiteboard to facilitate information-sharing between the researchers and the technologists. My original plan for a face-to-face workshop was changed to an online format after consultations with the supervisory team, the research team from Universiti Putra Malaysia and the technologists. The main reason for this decision was the travel and movement restrictions resulting from the COVID-19 pandemic. However, an additional advantage was that it allowed participants from different locations and time zones to participate.

The patients were from two urban public primary care clinics in central Malaysia. Asthma is managed in primary care clinics, which provide chronic and acute care management. The use of an asthma action plan to support asthma self-management was outlined in the local guideline \cite{22} and was implemented where it was available. Malaysia has a dual-health system, public and private, where the public health system provides services for the population with co-payment of MYR 1 (GBP 0.17) per visit. Section 2.4.2 provides further information about the Malaysian healthcare system.

9.4.3 Sampling and recruitment of participants

Every other patient from the Klang Asthma Cohort was contacted and had the study explained to them over the phone. Section 1.1 provides a description of the Klang Asthma Cohort. I allowed two weeks for potential participants to consider participating; potential participants were given a contact number and asked to call it to indicate their interest to participate in Stage 1 discussion and/or testing of the prototype in Stage 5. Inclusion criteria for patients invited for this study were that they should have physician-diagnosed asthma, be aged over 18, be a smartphone user, and have limited health literacy (screened using \textit{Bahasa Malaysia} language version of the HLS, HLS-Q47 \cite{43}). Section 2.2.2 provides an explanation of this health literacy tool, its measurement and its psychometric properties. I recruited five participants who fulfilled the inclusion criteria; three chose to attend both the Stage 1 discussion
and the testing of the prototype in Stage 5, and two agreed to participate only in testing the prototype in Stage 5. I led the Stage 1 discussion, and the members of this discussion were two healthcare professionals, two technologists, and four researchers from Universiti Putra Malaysia. The healthcare professionals were conveniently sampled, and they were healthcare professionals who cared for asthma in the primary care settings.

9.4.4 Design Sprint method and the data collection

I collected demographic information from the Klang Cohort database for those patients who agreed to participate. Table 34 outlines the objectives of each stage, the stakeholders involved, and the adaptations for online delivery.

In Stage 1, through a structured discussion between patients and healthcare professionals, we first discussed and agreed on the workshop’s long-term goals for the prototype and on our aims as a team. Then, we compiled a list of problems about self-managing asthma from stakeholders’ (patients and clinicians) perspectives. I also included problems about self-managing asthma from previous literature and findings from this PhD programme of work (the systematic review and qualitative study). Stakeholders’ discussions in Stage 1 focused on challenges for patients and healthcare professionals around:

i) asthma education;
ii) asthma self-management;
iii) monitoring of symptoms;
iv) emotional support/lifestyle advice;
v) social support; and
vi) clinic set-up.

We created an end-to-end process for how patients managed their asthma, focusing on the problems for which the mobile app could potentially provide solutions (Figure 44).

In Stage 2, focusing on the solutions to the problems identified in Stage 1, each researcher reviewed existing solutions (from the literature and commercially available health-based apps) that we would potentially
incorporate in the app prototype. Subsequently, each researcher presented their solutions as well as the explanations for their selection. We then drew rough sketches inspired by the review of existing solutions we conducted earlier. Following the presentation of the sketches and having critical conversations, we voted and included several sketches that were suitable to incorporate the contents for the prototype (Figure 45a).

In **Stage 3**, the winning sketches and content included topics such as asthma education, asthma symptom monitoring and asthma support were compiled. We created an end-to-end process (storyboard) for how these winning sketches and content would appear on an app. The storyboard was first written in text form before being turned into a graphic representation (Figure 45b).

In **Stage 4**, I assigned roles to each researcher from Universiti Putra Malaysia and the technologist, to ensure the successful development of the low-fidelity prototype for the testing process on the final day. For example, along with PYL and SSG, I reviewed the utility and usability prompts while the technologist built the low-fidelity prototype. We then tested the technical aspect of the prototype and reviewed the process as a group.

In **Stage 5** (Table 34), I tested the prototype during one-on-one interactions with five individual patients to assess its utility and usability, using a set of semi-structured questions in a concurrent ‘think-aloud’ interview format [264] (Appendix 23). The think-aloud method is a cognitive interviewing paradigm that involves encouraging respondents to verbalise their thoughts, without probing or additional explanations [264]. Thus, it allowed participants to express thoughts that they might not otherwise have expressed, and it allowed me to learn about participants’ thought processes while using the app without being directive (especially when they ran into problem and tried to solve it). Apart from the think-aloud method, a number of methods have been used for previous digital health interventions, including questionnaires, task completion, interviews, heuristic testing and focus groups, with questionnaires being commonly used [265].
During this session, as the main interviewer, I guided the process, while four other researchers (PYL, SSG, ATC and JW) observed the interview, and the two technologists (AG and MM) managed the sessions' technical aspects. Each interview took one hour, and they were all conducted in Bahasa Malaysia, the patients’ preferred language.

The group discussion in Stage 1 and the five think-aloud interviews (Stage 5) were audio-recorded, other online discussions and browsing activities were video-recorded, and online board exercises were captured and archived. All interviews were subsequently transcribed verbatim.

9.4.5 Data analysis

I used thematic analysis to obtain rich data from the stakeholders’ discussions in Stage 1 and the interviews in Stage 5. The texts were analysed iteratively using a deductive thematic analysis approach, as outlined by Braun and Clark (2019) [266]. A deductive thematic analysis seeks to answer the researcher’s theory or analytical interest within the topic [266]. Phases in the thematic analysis included the following [266]:

i) familiarisation with the data by reading, re-reading and noting down initial ideas (memoing);

ii) duplicate coding (HS and JW) of one interview and comparing decisions, to agree on a standardised coding framework before coding all the transcripts;

iii) discussing emerging themes with the research team;

iv) reviewing themes with the wider research team and generating a map of the analysis (HP/SSG/PYL/ATC/IY);

v) defining themes, which was achieved iteratively;

vi) presenting the deductive analysis, with a selection of extracts.

The data were organised using QSR NVivo 11 qualitative data analysis software.
9.4.6 Patient and public involvement (PPI)

I presented the plan for this project during a RESPIRE stakeholder engagement event in Malaysia, and it was well-received. The event was attended by healthcare professionals, healthcare administrators and members of the public.

For the Design Sprint workshop, I initially met with a PPI colleague, who had attended the above event, to discuss the Design Sprint workshop’s delivery. In the original proposal, the Design Sprint workshop included large group discussions (all stakeholders, including healthcare professionals and technologists), presentations using PowerPoint, whiteboards, posters, and the use of colourful sticky notes for voting on ideas for the intervention’s design. The PPI colleague proposed employing small-group discussions among people with asthma, to provide a safe environment for discussion about how the intervention could be adapted to their specific requirements. In addition, having a homogeneous small-group conversation before a large-group discussion may help eliminate any power imbalance between group members (e.g., between patients and doctors). The remainder of the PPI panel assisted in reviewing the participant information sheet, consent forms and workshop itinerary.

Moreover, their contributions were critical when the workshop was adapted to an online format due to the COVID-19 pandemic. The ideas suggested, which I included in the workshop’s execution, were training for all online platforms and software utilised for the workshop, financial assistance for internet data plans, and participation of people with asthma on selected important stages. During the training sessions, I listened to potential participants’ feedback about the challenges of involvement in a full-day workshop (9 am to 5 pm) over five days. The constraints included their personal commitments to employment, home-schooling of children and other family caring tasks during the lockdown. Following the training sessions, I decided, in consultation with the technologists and the other researchers, that participants with asthma should only attend Stages 1 and 5. Their participation in these two stages was critical.
for two reasons: Stage 1 was where they provided feedback on what content and format should be included in a mobile app to support asthma self-management, and Stage 5 was where people with asthma tested the prototype while providing feedback in a concurrent think-aloud process.

9.5 Results

Five patients (including the three who attended Stage 1) participated in Stage 5 (prototype testing). Table 35 summarises the demographics of patients involved in Stage 5.

Table 35 Demographics of patients involved in Stage 5.

<table>
<thead>
<tr>
<th>ID</th>
<th>Age</th>
<th>Gender</th>
<th>Health literacy level†</th>
<th>Use of pictorial asthma action plan for 6 months</th>
<th>Access to a digital device</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>44</td>
<td>Woman</td>
<td>30</td>
<td>Yes</td>
<td>Smartphone and PC</td>
</tr>
<tr>
<td>P2</td>
<td>36</td>
<td>Man</td>
<td>32</td>
<td>No</td>
<td>Smartphone</td>
</tr>
<tr>
<td>P3</td>
<td>40</td>
<td>Woman</td>
<td>17</td>
<td>Yes</td>
<td>Smartphone and PC</td>
</tr>
<tr>
<td>P4</td>
<td>38</td>
<td>Man</td>
<td>21</td>
<td>No</td>
<td>Smartphone</td>
</tr>
<tr>
<td>P5</td>
<td>19</td>
<td>Man</td>
<td>31</td>
<td>No</td>
<td>Smartphone and PC</td>
</tr>
</tbody>
</table>

Note: A score less than 33 is considered as limited health literacy†

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9.5.1 The outcomes of each stage

Stage 1: Understanding and mapping problems

Figure 44 illustrates the Stage 1 process, and Appendix 24 illustrates the whole process. Three patients and two healthcare professionals (a family physician and a medical officer from Klang District) contributed to the stakeholder discussion. The stakeholder discussion themes were categorised as relating to individuals, family and friends, society, and systems (Table 36). I used the key problems that featured in this discussion to inform the app design, including education sources for asthma, support in the community, enabling
self-management using pictorial action plans, reminders for medications, and asthma reviews or follow-up consultations. Some of these solutions were related to the problems or recommendations I found in the framework analysis (Section 7.4.2): for example, the use of an alternative format to a written action plan and signposting to reliable information on asthma. In addition, logs of history of asthma control, preventer intake and information on expected best peak expiratory flow rate (PEFR) were features that could support patients during follow-up consultations with their healthcare professionals.

**Figure 44 Stage 1 process: Understanding and mapping problems.**

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Table 36 Themes from the stakeholders’ discussion.

<table>
<thead>
<tr>
<th>Level</th>
<th>ASTHMA SELF-MANAGEMENT</th>
<th>ASTHMA MONITORING</th>
<th>EDUCATION</th>
<th>EMOTIONAL SUPPORT/LIFESTYLE ADVICE</th>
<th>SOCIAL SUPPORT</th>
<th>CLINIC SET-UP</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Individual level</strong></td>
<td>help patients remember their appointments and adherence to medications using technology?</td>
<td>help patients to monitor their symptoms?</td>
<td>help patients identify their triggers?</td>
<td>motivate patients to continuously engage with asthma care?</td>
<td>create awareness about social support for people with asthma living in the community?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>assist patients on how to act during exacerbations?</td>
<td>assists patients to manage their symptoms in an interactive manner? (e.g., live chat with health professionals, teleconsultation)</td>
<td>deliver knowledge about asthma and its control effectively to patients?</td>
<td>assists patients to cope with their activities of daily living?</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Family and friends</strong></td>
<td></td>
<td></td>
<td>create and improve family awareness about the potential serious impact of poorly controlled asthma?</td>
<td>effectively engage family members in asthma care?</td>
<td>assist patients to get better social support from peers and social network?</td>
<td></td>
</tr>
<tr>
<td>Society</td>
<td>System level</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---------</td>
<td>-------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>create and improve public awareness about the potential serious impact of poorly controlled asthma?</td>
<td>reduce healthcare professionals’ workload in asthma care?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>assist patients to access the social support that is available in society?</td>
<td>provide healthcare professional with asthma control assessment to monitor patients?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>create monitoring systems that could provide advice which corresponds to current situations? (e.g., COVID-19, haze)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>assist healthcare professionals to have better knowledge about sources of support for patients?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>create an app to reduce healthcare professionals’ workload?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>provide dedicated asthma clinics for all patients?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>provide multidisciplinary care?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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**Stages 2–4 Sketching, designing and developing the prototype**

The conduct of Stages 2-4, which used various online platforms, is described in Table 34. Informed by the stakeholder discussion and what was learned from previous projects, I worked with the team of researchers through the stages of sketching solutions, deciding on solutions to problems, and designing and developing the prototype (Figure 45 a and b). Through a round of voting in Stage 3, solutions supporting self-management based on evidence-based practice were selected [17]. All the winning solutions were clustered around four aspects of care (Table 37):

i) education;
ii) supporting self-management;
iii) supporting behaviour change; and
iv) social support.

We created a storyboard for the prototype, and based on the storyboard, we developed the prototype app, for testing in Stage 5.

The whole process is illustrated in Appendix 24, and the decisions on prototype content are summarised in Table 37. The app was written in the *Bahasa Malaysia* language. Considering the findings of the qualitative study and Stage 5 of the Design Sprint workshop, the formal *Bahasa Malaysia* language may not be understood by all. As a result, simple instructions accompanied by icons overcame the challenges associated with language use in this multilingual society.
Figure 45 Stages 2 and 3 of the Design Sprint workshop.

a. Stage 2: Sketching solutions:

b. Stage 3: Deciding on solutions to the problem:

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Table 37 Asthma app content and design features.

<table>
<thead>
<tr>
<th>Main theme</th>
<th>Section</th>
<th>Content</th>
<th>Features</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td>About asthma, its symptoms and diagnosis</td>
<td>Information in text and videos about asthma, symptoms, triggers, how the diagnosis is made, exacerbations and myths around asthma attacks. Other information includes types of medications used to treat asthma, their function and potential side effects. There will be video-based instructions on inhaler technique.</td>
<td>The links to the Ministry of Health portal on asthma are provided under specific headings to facilitate the search for reliable information.</td>
</tr>
<tr>
<td>Asthma medications</td>
<td>The links to the Ministry of Health portal on asthma are provided under specific headings to facilitate the search for reliable information.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supporting self-management</td>
<td>Self-monitoring of symptoms</td>
<td>Patients indicate any experience of asthma symptoms in the last 24 hours, which will translate into an indication of asthma control level and prompt checking of the action plan.</td>
<td>Tick-box list of potential asthma symptoms; ticking any one symptom will prompt a pop-up on advice to look at an action plan with a click button.</td>
</tr>
<tr>
<td></td>
<td>Asthma action plan</td>
<td>Illustrations and wording were previously validated in discussions with stakeholders.</td>
<td>List of zones are displayed, and patient chooses which zone is appropriate for them.</td>
</tr>
<tr>
<td>Supporting behaviour change</td>
<td>Asthma medication and appointment reminder</td>
<td>Patients provide information about medications and follow-up consultations, which triggers reminders at the timing of choice.</td>
<td>Matrix of images of medications used and drop-down menu for frequency and timing.</td>
</tr>
<tr>
<td></td>
<td>Asthma diary</td>
<td>Asthma control and medication uptake will be recorded in the diary, including best peak expiratory flow rate (PEFR).</td>
<td>Monthly calendar, which displays asthma control and adherence.</td>
</tr>
<tr>
<td></td>
<td>Reward system</td>
<td>Achieving good asthma control and medication adherence will be translated into points.</td>
<td>Display of scale of points achieved for good asthma control and adherence.</td>
</tr>
</tbody>
</table>
Stage 5 Testing the low-fidelity prototype

I invited patients who attended Stage 1, and two other patients, to attend Stage 5. Results are presented under the two main themes of utility (did the app influence or support self-management?) and usability (how easy was the app to use?).

- **Utility**

Patients commented that the app influenced the decision to self-manage in four ways: offering information, providing an accessible asthma action plan, motivating and supporting improved medication adherence, and promoting behaviour change through a reward system.

*Offering information*

Patients considered that the app provided essential information regarding asthma and how to manage it. P4 explained, ‘*The information about asthma in the app is interesting and informative*’. What most interested the participants was that the app provided all the information in one place. P1 said, ‘*Sometimes people are lazy to search here and there, to know more about asthma. In this app, all the information is there, and I can open it anywhere, just like the way I use WhatsApp*’. Although many were comfortable reading text-based information, some preferred audio-visual formats such as video. P5 explained, ‘*The information about asthma, maybe it can be in the video, it’s more interesting than just words*’.

*Providing accessible asthma action plans*

Patients felt that having the action plan on the smartphone made the plan accessible when needed. As P1 described, ‘*When you need the plan, you just*...
open the app in your phone and click on the [action] plan, to see it’. In this format, patients considered the action plan easier to access and use than the paper-based action plan, which they may not carry unless attending asthma follow-up consultations.

**Motivating and supporting improved medication adherence**

The medication reminder function of the app was viewed as a useful support to achieving good adherence to daily preventers (Figure 46). For example, P5 stated, *It will be difficult not to remember taking the medications because of the reminder, and because I use the phone frequently, it is hard to ignore the reminder (chuckled)*.

Some participants noted that charting their level of asthma control and adherence in the form of a calendar would assist communication with healthcare professionals. As P3 put it, *When I see the doctor, I can show them the chart from the app. How’s my asthma control and did I take my medications regularly. In a way, this helps me to motivate myself to do what I’m supposed to do to care for my asthma*.

**Figure 46 Components to support medication adherence.**

Original photographs of asthma medicines are used to aid in the storage of information (Frames 1, 2 and 3). Component of promoting adherence with prompts that people can arrange around their schedules (Frames 3 and 4).
Promoting behaviour change through a reward system

The app was designed to encourage behaviour change through a positive reward system, in which good asthma control and adherence to twice daily preventive inhalers would be awarded points, and the cumulative points were visualised clearly. Patients liked this approach. P1 was very excited to see the reward points on the app: ‘Wow, there are reward points, this is great!’ This excitement was shared by other patients who preferred to see tangible results of their actions. P3 elaborated on how the reward system could influence behaviour: ‘That’s nice when I get points for taking the medications. I do want to see that I accumulate points and the scale moved further. And I can only do this if my control is good and if I take my medications’.

• Usability

The patients could easily comprehend information and instructions in the app. P2 elaborated on how he achieved this: ‘The instructions are accompanied with illustrations. It makes it easier to understand it’. Although patients liked the use of illustrations and relatively few words, the small font size was challenging for some. P1 said, ‘The writing is small. I tried to put on my glasses, I still can’t see it (chuckled)’. We used cartoon-based illustrations of the medications in the steps of the asthma action plan. Some suggested that the pictorial asthma action plan may be useful for patients with asthma who are not adults. P3 suggested, ‘I think the illustrated plan can be appealing and useful for children and their carer. It’s very easy to understand.’

Figure 47 illustrates an example of how a participant browsed through the low-fidelity prototype during the testing session. The participants pointed out that a lack of navigational symbols meant that it was not always clear how to move from one interface to another. P4 stated his confusion: ‘There is no sign or indication on what to do next. I was a bit lost on what should I do now. Perhaps an arrow would help to tell that I can move forward’. Otherwise, patients were mostly satisfied with the simple layout. P1 gave an example of this: ‘In terms of the layout, it’s quite easy to navigate around the app. It’s OK for me.’ All
information was presented in a box-ticking manner, and it was displayed against a pastel-coloured background, a colour choice that many found appropriate.

The time spent using the app varied (10–45 minutes). Some (younger) patients seemed comfortable navigating from one interface to the other and were keen to click buttons to explore the app functions. In contrast, others were dependent on symbols or prompts to navigate, which the app lacked at the testing stage.

The language used in the app was generally satisfactory, although there was a linguistic misunderstanding of ‘breathlessness’ and ‘wheeze’ in the Bahasa Malaysia language. P4 described his confusion about the Bahasa Malaysia words for breathlessness and wheeze: ‘Mengalami sesak nafas [breathlessness] and lelah [wheezing], are different? I thought it’s the same thing?’
After the workshop

After the testing stage, the design was refined and developed. Figure 48 depicts an example of the refining process of the mainframe of the prototype app. I made all the final decisions on the design and the content in consultation with the supervisory team and the research team from Universiti Putra Malaysia. The coding and development of the app was conducted by a team of third-party technologists. The team met every two weeks to discuss the progress of the prototype app and to resolve issues regarding design and content. The prototype app was finalised after three months (Figure 49). In the prototype app, I decided to use more images (e.g., picture of medications) and navigation cues (text and symbols) based on the patients’ feedback.
addition, I added information on PEFR as part of the guideline-recommended practice and to assist healthcare professionals’ management.

*Figure 48 the refining process based on participants’ feedback.*
Figure 49 The finalised app design.

Examples of the app interface after the refining process

a. **Mainframe with medication reminders:**

b. **Medication listing:**

c. **Information on PEFR:**

d. **Pictorial asthma action plan:**
9.6 Discussion

9.6.1 Summary of findings

I planned and conducted a Design Sprint workshop and employed an online format to ensure the researchers and patients’ safety during the global pandemic. In this five-stage workshop, my team and I developed a low-fidelity prototype based on theoretical frameworks and refined it based on patient feedback during the design and testing stages. Patients described the resultant app as potentially able to influence their ability to self-manage in four ways: offering information, providing accessible asthma action plans, motivating and supporting improved medication adherence, and promoting behaviour change through a reward system. Specific usability issues were related to navigation, comprehension and layout.

9.6.2 Strengths and limitations

Overall, the five-day Design Sprint method allowed the development and testing process to be done quickly and efficiently at low cost – an important consideration, especially in a low-resource setting. As described in Section 9.2, one of the Design Sprint method limitations is that it does not describe further evaluation, such as testing for feasibility and clinical effectiveness. However, I used the 6SQuID framework as an overarching framework to inform this PhD programme of work (see Figure 41). The Design Sprint method falls into Step 4 of the 6SQuID framework, and Steps 5 and 6 of the 6SQuID framework cover the aspect of further evaluation of the prototype to ensure robust evidence to inform practice.

Participants and language

The involvement of stakeholders and the multidisciplinary approach at the development stage in the Design Sprint method, which are among the strengths of this study, may increase the chances of the intervention meeting the needs of the target population.

The limited number of participants posed several limitations. Firstly, the limited number of stakeholders, particularly people with asthma, may limit
comprehensive feedback or exploration of more nuanced opinions about the intervention design, thus limiting the generalisability of my findings. I also acknowledged that the researchers and healthcare professionals outnumbered patients with asthma, which might have affected the power balance in the discussions during the stakeholder discussions in Stage 1. To overcome this challenge, each participant was given dedicated time to express their view and was invited to use the chat function to write down their opinions if they wished. I found that patients were comfortable expressing their views and were actively engaged in the discussion beyond the designated time. However, none of the participants used the chat function. In the testing stage (Stage 5), the number of responses was insufficient to conduct a quantitative evaluation, but the qualitative analysis provided insight into the intervention design features that participants liked and found practical to use.

In terms of diversity of participants, I recognised that in this workshop, I did not have any participants over the age of 50, possibly because this digital approach was more appealing to younger age groups, thus, the findings may not reflect the feasibility of using online methods for older age groups, especially those with limited health literacy. Inevitably, this will have limited the views that contributed to the design of the app. However, in the qualitative study, several older persons found the value in adopting technology to manage their health, such as a mobile app – a favourable view on the role of digital technology to support older adults with asthma self-management.

Apart from the lack of participants who were patients with asthma in this workshop, no participants from Indian or Chinese ethnicities participated in the workshop, despite patients from these ethnicities having expressed interest during recruitment. Thus, the findings from stakeholder discussions and testing of the app may not be generalised to people with asthma who are of Indian and Chinese ethnicities. However, multicultural identity was highlighted when one participant described the need for a multilingual app for ease of use for those speaking other than Bahasa Malaysia. The prototype was developed using the Bahasa Malaysia language due to financial constraints. The use of
images and symbols in the prototype, to a certain extent, may bridge the language barrier to use the app among other ethnicities. Funding for further development needs to factor in the use of a multilingual app to meet the needs of the multilingual population.

The pandemic context may have explained the sampling challenges (e.g., age and ethnicity) and the relatively small number of participants I could recruit. In addition, some participants found it challenging to commit uninterrupted time to an online workshop while ‘locked down’ at home with their domestic, caring or home-schooling responsibilities. Because of the lack of diversity among participants in this workshop, the findings from Stage 5 could not be generalised to represent the population. For comparison, face-to-face intervention design workshops have been reported with 14 participants at 5-stage workshops [267] and 38 participants over six weeks [268]. However, socio-cultural factors may affect willingness to participate in group discussions; for example, as noted in Section 6.3.7, PPI members described their concerns about potential participants’ socio-cultural norms inhibiting their willingness to share with others, especially in a group the details about their health.

**Testing stage**

During the testing stage (Stage 5), although the think-aloud process I used enabled explorations of views, it has its limitations. Participants might not consistently express their thoughts during the think-aloud process, and information may be missing or insufficient. I employed a checklist of usability and utility prompts to overcome this limitation. With the online approach, as outlined in Section 9.4.4 and further elaborated in Section 9.6.3, other researchers were able to observe the testing of the prototype with their cameras turned off and taking field notes of what they observed, which we discussed after each interview before moving on to the next interview.

Another factor was that the technologist prepared a low-fidelity or modelled prototype for testing. Constructing a low-fidelity prototype offered many advantages in the initial stage of prototype development: it allowed a prompt
gathering of requirements, ideas and concepts, and it could be built rapidly [263]. The disadvantage was that the low-fidelity prototype lacked some core functionality (such as navigation features), so that the patients on day five were giving feedback on a limited version of the app. Nevertheless, incorporating the participants’ suggestions was beneficial and enabled the low-fidelity prototype to be refined in a timely manner after the workshop to produce a high-fidelity prototype.

**The online approach**

Originally, participants were invited to all five days of the workshop and did not require any pre-workshop training. However, in this online workshop, not all stakeholders participated in every stage. The constraints of time and resources limited the number of participants and engagements I could incorporate in every stage of the workshop.

In term of the strengths, the online approach connected people in different geographical locations and ensured safety during the global pandemic. However, the requirement for an internet connection was a barrier to participation, which I recognised and discussed with the PPI member. I overcame limited internet access by providing participants with internet data vouchers, but I had to exclude those with no access to any digital devices. With assistance from the technologists, we provided training on the various platforms for the workshop, thus overcoming participants' lack of digital skills. These strategies and strengths would reassure researchers and intervention developers working in countries or settings with high levels of limited health literacy that this online methodology is of value.

**9.6.3 Interpretation of results and comparison with the literature**

*Designing an asthma app for people with limited health literacy*

In the context of supported self-management among people with asthma, this study contributes to the understanding of how digital health could provide support to the needs of people with limited health literacy. Mobile apps are
more likely to appeal to patients if they include features that the users value [269]. I therefore prioritised understanding the needs of the target population and the features they wanted to see in an asthma self-management mobile app to meet those needs. This exercise was reflected in Stage 1 of the Design Sprint method, in which healthcare professionals and patients were invited for dialogue with the researchers. The sharing session and learning points from the systematic review and the qualitative study described in previous chapters enabled understanding of the challenges of living with asthma and were helpful to inform subsequent stages of the work.

A low-fidelity prototype was developed with assistance from the technologist and in discussion with the researchers during this workshop. The low-fidelity prototype was the version that I tested with patients on day five and which was subsequently refined based on feedback from five participants to produce a high-fidelity prototype. The focus was on testing the prototype’s usability and utility. Usability refers to the app’s ease of use, whereas utility refers to the app’s ability to influence or support asthma self-management. I used a think-aloud process to explore problems that needed to be addressed in both aspects [264]. Section 9.4.4 provides a description of the think-aloud method. For example, a participant commented that he found moving from one interface to another during the testing challenging. He then suggested using arrows to ease navigation, a feature that was absent in the low-fidelity prototype, as well as making a suggestion about the arrows’ size and position at each interface. Although usability and utility evaluations using questionnaires are widely used [265], the think-aloud process has the advantage of capturing issues in content and technology that are not captured in usability questionnaires. Such information was useful for the refining process I intended for the app.

During the design workshop, the prototype app development process was focused on designing and delivering a pictorial asthma action plan, as a core strand of tailoring supported self-management to people with limited health literacy. This aspect was one of the advantages of the prototype, as asthma
apps featuring asthma action plans were reported to be uncommon [84], and this was reflected by the findings of a review of online forums on app features that patients wanted [256]. Hui et al. noted that most patients wanted self-monitoring features, including logging peak flow, medication and symptoms, and monitoring for triggers, but patients did not describe asthma action plans [256]. It is thought that this is because the lack of an asthma action plan feature in commercially available asthma apps might result in a lack of awareness and use of asthma action plans. However, the review by Hui et al. described the preferences of people with asthma from a high income setting and not specifically those of people with limited health literacy.

Other features were the use of simple language for symptom assessment, education and information resources, provision of visual and audio medication reminders and inclusion of practical behaviour change strategies, such as a reward system. In the United States, a study found that action plans were written at the literacy level of a sixth-grader (11 to 12 years old), representing a challenge to those without formal education or with only primary school education [74]. The same study also found that featuring more graphics within an action plan may be needed to increase ease of use [74]. In this intervention design workshop, the use of pictorial action plans and employing simple language were among the strategies used to overcome the challenge in understanding a written asthma action plan.

Adaptation of the Design Sprint workshop to an online format

Patients with asthma and healthcare professionals had been recruited for a face-to-face workshop in March 2020, but this could not take place due to the lockdown imposed by the local authority in response to the COVID-19 pandemic. In consultation with the supervisory team, the research team from Universiti Putra Malaysia and the technologist, I adapted the workshop to an online format. A high-speed internet connection and technical skills in conducting this workshop were vital to minimise the potential impact on participants’ research experience [270]. To overcome some of these practical issues, I supported each participant with mobile online access through a MYR
10 (GBP 1.86) internet data voucher, to ensure the participants would not bear the cost of internet access. I also conducted training sessions to avoid technical problems during the workshop.

In the context of interviews, the literature suggests that online data collection can produce data of a similar quality to that produced by face-to-face interviews [270]. Although using an online platform to interview patients was a new experience for the researchers, I found that the online programmes eased discussion, and interviews took place quickly and effectively. One advantage, compared to traditional qualitative interviews, was that other researchers could observe the interview sessions in the online platform (with the consent of the participant), and they could make concurrent fieldnotes. From the patients’ feedback, although they knew they were being observed by additional researchers, being in their own homes helped them to forget about being observed and reduced anxiety.

In online discussions and interviews, dictation software has been used to capture the audio data in text format, reportedly avoiding transcription errors [271,272]. However, this was not possible in this context because the medium of interaction was the Bahasa Malaysia language, and the extensive use of this non-standard but commonly spoken language made it impossible to use any dictation software. Conducting research online raises concerns about participant confidentiality and data security. I ensured that entry to the workshop was password-protected to securely control access to maintain the participants’ confidentiality. Recordings were stored securely. For example, files from the workshop were encrypted and stored in a secure research data storage facility at the University of Edinburgh.

On a practical level, to help researchers’ concentration throughout the five 9-hour days of the workshop, I included frequent breaks and provided high-energy snacks. Each session was one hour, followed by a 15-minute break, or 45 minutes long, followed by a 10-minute break. Committing to time in a workshop alone in front of a computer monitor can be challenging and mentally draining, so a week before the workshop, each researcher and technologist
received a supply of high energy snacks through the post (Figure 50). I also provided coloured sticky notepads and permanent markers with similar tip sizes to ensure all scanned sketches and written notes were clear when uploaded to the online discussion board.

**Figure 50 Snacks and stationery for the workshop.**

9.7 Summary and next step

In this chapter, I have described the development of the intervention using the Design Sprint method. It proved possible to adapt the Design Sprint method to an online format using various programmes that allowed the development and testing processes to be done efficiently and securely. The resultant app, on the advice of stakeholders, included sources for information about asthma, medication and appointment reminders, accessible asthma action plans and sources for social support. The app was tested and further refined to include specific features, such as sources of information on asthma, a pictorial asthma action plan, simple language, audio-visual prompts and rewards to support adherence to daily therapy and scheduled reviews. Despite practical challenges, a five-day online design workshop proved to be manageable, enabling meaningful engagement from patients and healthcare professionals so that a prototype is now ready for feasibility testing. A feasibility study may be needed to gauge the health literacy tailored self-management mobile app’s
effectiveness in improving asthma outcomes in clinical practice. In the next chapter, I summarise and discuss the complete PhD programme of work.
Chapter 10 Thesis discussion and implications.

In this chapter, I summarise the principal findings from the systematic review, the qualitative study, the change mechanism and the Design Sprint method chapters in relation to the PhD objectives. Then, I highlight the strengths and limitations of the thesis overall and discuss its key findings in relation to published literature. Finally, I will consider implications for patients, policymakers, healthcare providers, clinical practice and research.

10.1 Summary of findings

Objective 1: To systematically search for and synthesise evidence of asthma self-management interventions aimed at individuals with limited health literacy:

- to evaluate their clinical effectiveness (Objective 1a), and
- to identify the behaviour change strategies used in the interventions associated with effective programmes (Objective 1b).

The systematic review presented the synthesised data from five studies, four of which were at high risk of bias. The only study at low risk of bias did not report health outcomes. I could not establish the overall effectiveness of any of my primary outcomes of interest due to study design limitations and the dearth of studies. Most studies [116,117,140] included in this review did not describe any theoretical framework underpinning the intervention development; however, one conducted prior exploratory work to understand health literacy’s impact on the targeted population [139]. Education, training and enablement were the functions used in these interventions. The content and delivery method varied, including video-based [117,139] and a pictorial action plan [140]. All the interventions used behavioural change components primarily directed at individuals’ (physical and psychosocial) capabilities; two addressed self-motivation; none targeted opportunity.
Objective 2: To explore subjective experiences of living with asthma among people with limited health literacy in Malaysia:

- *to explore the experience of living with asthma (Objective 2a).*

Three themes were identified in the narrative approach to analysis. The concept of autonomy was central to all themes; the participants expressed a desire to have the power to control and make decisions about their health. The themes identified in this analysis were the following:

i) Asthma is a life story;

ii) Reclaiming identity in the network of everyday relationships; and

iii) Redefining interactions with the health system and environment.

Asthma was described as a lifetime of learning to manage the symptoms and the physical and mental challenges asthma brings. The study participants felt a loss of identity, mainly regarding occupational roles and fulfilling societal expectations. As people living with asthma, participants reported being unable to avoid interacting with the health system, but their lack of knowledge about health posed a significant barrier to communication within these interactions. Managing environmental challenges was an aspect that participants were aware of but which they lacked the skills, knowledge or financial means to negotiate.

- *To explore the role of health literacy in understanding asthma and how it influences self-management decisions (Objective 2b).*

The health literacy framework analysis explored the role of health literacy in negotiating medical narratives and social practice in asthma management decision making. Participants used formal and informal sources to access information about asthma and self-management. Struggles with language (both ‘jargon’ and lack of translations) affected understanding of written information, while good communication with a healthcare professional could help overcome this. Understandings about asthma and perceptions of control were predominantly based on health beliefs, with limited science-based understanding of the condition. Most participants did not explicitly describe strategies to evaluate or check health information they received and instead
‘just followed’ professional advice, though a few drew on experiential knowledge to help evaluate the information they received about asthma. In applying information about asthma, established self-management practices were mixtures of scientific knowledge and culturally determined health practices.

- To identify barriers to using evidence-based self-management plans among people with limited health literacy and to identify how the use of such plans can be supported (Objective 2c).

Lack of awareness and not being prescribed a written asthma action plan prevented its use among most participants. Those with experience of using a written asthma action plan described challenges in understanding it and questioned its practicality in their daily lives. Recommendations to improve awareness, adoption and use of written asthma action plans included active provision by healthcare professionals supported with tailored education and training for the patient, family involvement, and an innovative format for the asthma action plan using every day, familiar technology. Social peer support had a positive impact on evidence-based self-management decisions.

**Objective 3: To design an intervention underpinned by a theory of change.**

Building on the previous literature, the systematic review and the qualitative study, I used Steps 1 to 4 of the 6SQuID model to define my intervention development. This exercise was informed by COM-B of the Behaviour Change framework. The intervention I planned to develop had multiple components delivered using a mobile app. I recognised the strong evidence that supports the likelihood of success using multi-component intervention, as compared to single-component intervention. Steps 5 and 6 were discussed in the context of future work.
Objective 4: To develop and refine a prototype asthma self-management app tailored to the needs of people with limited health literacy:

- to optimise user experience in prototype development by integrating patients and health professionals in the process (Objective 4a),
- to model key aspects of the prototype and test to identify utility and usability issues (Objective 4b), and
- to refine and develop the prototype app (Objective 4c).

Despite practical challenges, a five-day online design workshop proved manageable, enabling meaningful engagement from patients and healthcare professionals so that an app prototype is now ready for feasibility testing. Furthermore, it proved possible to adapt the Design Sprint workshop to an online format, which had the added advantage that it allowed the development and the testing process to be done efficiently through various web-based programmes (Objective 3).

The low-fidelity app prototype incorporated advice from stakeholders, including a culturally tailored pictorial asthma action plan, sources of information on asthma, medication and appointment reminders, and information on social support. The low-fidelity app prototype was a low-function prototype that used simple technology but was sufficient for initial testing. Working alongside the technologist, I refined the components based on the feedback received during the test. The refined prototype includes specific components such as video-based information on asthma, using simple language and icons, audio-visual prompts and rewards for supporting adherence to daily therapy and scheduled reviews.

10.2 Strengths and limitations of the study

The strengths and limitations of the component projects in this PhD work are discussed in detail in the project-specific chapters (Sections 5.5.2, 6.5.2 and 7.5.2). In this section, I discuss the strengths and limitations of the overall programme of work.
10.2.1 The choice of the overarching framework

A strength of this PhD was its use of diverse study designs to answer the research objectives, guided by an overarching framework, the 6SquID model [107]. As described in Section 4.2.2, the 6SquID model provided a systematic process and detailed description to develop an intervention based on pre-defined findings from my systematic review and the qualitative work. Each of the proposed steps was broken down into sequential actions which were practical and easy to execute. Although initially I was more familiar with the MRC framework and planned to use this, the original guide for the MRC framework did not provide explicit guidance on how to carry out and complete the development stage of the framework (as explained in Section 4.2.1) [101,102]. However, an updated guideline on the developmental phases was published in 2019 [106]. I identified two key principles of the developmental guideline which strengthened the MRC Framework and compared it with the 6SQuID model:

i) There is an emphasis on a dynamic, iterative process of intervention development [106] whereas, the 6SQuID model’s process is conceived as linear [107]; and

ii) The involvement of stakeholders throughout the development process [106] is missing in the 6SQuID model [107].

To overcome these limitations, the Design Sprint method [108] was employed within the 6SQuID model as it allowed an iterative process of the prototype App development (e.g. development and refining as the testing in Stage 5). The rationale for devoting time to multiple iterations is that challenges can be identified and solutions found before subsequently embarking on any costly feasibility or evaluation phase [106]. Furthermore, the conduct of the Design Sprint method took into account early user experiences in the development of the prototype [108] (e.g., stakeholder discussion in Stage 1). The rationale for involving key stakeholders from the commencement of intervention development, and working closely with them throughout, is that they can help pinpoint priorities, understand the problem and seek solutions that will make a difference in real-life implementation [106]. Section 10.3.5 gives details of the
wider stakeholder engagement for this PhD programme of work. In conclusion, when this PhD programme of work was conceptualised, the 6SQuID model was the best framework to inform its conduct. However, the new developmental guidance [106] (and the very recent publication of the new MRC framework [273]) may have been a good alternative to fulfil the need for iterative prototype development and stakeholder engagement in the process.

10.2.2 Methodological aspects related to study designs

Systematic review

The systematic review is a strength of this PhD programme of work, as it defines the current understanding of the interventions addressing limited health literacy to improve asthma self-management. However, due to the small number of relevant studies and methodological limitations, I could not establish the overall effectiveness on any of my primary outcomes of interest. All the included studies were controlled trials, though I would have accepted other experimental study designs. Although I updated the search in October 2019 due to the fast-paced nature of the technology field and as COVID-19 has accelerated the use of digital technology in healthcare, the review could have missed some recent interventions especially using digital technology, which later in the programme of work I chose as my preferred mode of delivery.

Qualitative study

The use of Photovoice is a strength of this programme of work. Photovoice is a participatory model of research and is essentially transformative. It has its roots in a radical pedagogical practice where people collectively gathered to articulate their experience in their terms – through their voice. In essence, it is a type of research led by participants.

My adaptations of Photovoice in this PhD programme of work enabled me to embed the photographs in the broader in-depth interviews, providing a rich understanding of participants’ experiences. I went on to use two forms of qualitative analysis. The narrative approach to analysis provided insights into
people’s subjective views of living with asthma and limited health literacy. Using the framework analysis helped me understand how health literacy works at the societal level (e.g., lack of analytical skills preventing access to evidence-based knowledge about health) and the gaps in meeting the demand by the health system (e.g., use of complementary and alternative medicine).

In an era of globalisation and social media, the abundance of health information coupled with a lack of analytical skills poses a threat to people with limited health literacy, as inaccurate information may hinder appropriate management and timely care. The framework analysis answered specific research objectives to provide information for the development of an intervention.

However, the adaptations may have limitations and may have influenced the findings. The conduct of Photovoice in this programme of work was more researcher-led than in the original Photovoice method. As a clinician, my role may affect the researcher–participant relationship. Such a relationship may potentially mimic the same kind of medical authority many participants referred to in their asthma consultations; so that the power dynamics inherent in the doctor–patient engagement around asthma management were likely to have been reproduced in the research encounter itself. To minimise the impact of the power imbalance on the research findings, I used several strategies described in the literature. Firstly, strategies described by Lincoln and Guba (see Section 6.3.6: Table 19) were used to ensure the patients’ voices were represented in the findings [193,194]. During interviews, I noticed that the use of photographs helped shift the power balance to the patient’s experience.

Finally, I reflected upon ethical and methodological strategies by Karnieli-Miller et al. at different stages of the research (for example, checking the accuracy of the descriptions of the photographs and preliminary themes with the participants) [274].

**Design Sprint**

The main strength of the Design Sprint method is the short length of time it is required to be completed. The Design Sprint workshop enabled me to develop
As described in Section 9.2, when the pandemic struck prior to the beginning of the workshop, I had two options: scale down the PhD programme of work by omitting the Design Sprint workshop and the feasibility work that would have followed or adapt the PhD programme of work. I had planned for a face-to-face format for the Design Sprint workshop in March 2020. However, due to its advantages, including its rapid development timeline and agile method, the Design Sprint method was easily adaptable into an online format, with support from the technologists (see Table 34 for adaptations to the online format). The online format allowed me to lead this workshop remotely from Edinburgh.

The other impact of the COVID-19 pandemic in the conduct of the Design Sprint workshop was the timeline for obtaining approvals. Due to the change in study design, the request for protocol amendment was considered substantial, and thus significant time was required for seeking approval from various research ethics committees in the United Kingdom and Malaysia. Considering that requests for COVID-19-related research were rightly given priority in the context of the ongoing pandemic, the process of gaining approval for other non-COVID-19-related research was substantially delayed. Such a delay imposed time limitations at this stage of the PhD programme of work with two significant impacts. Firstly, I could only conduct one cycle of testing the low-fidelity app prototype; ideally, several iterations could identify usability and utility issues that could be solved. Secondly, the delay meant that I was unable to proceed to a planned feasibility study.

10.2.3 Patient and public involvement (PPI)

One of the strengths of this PhD programme of work is the involvement of PPI. PPI is a relatively new concept in Malaysia, which limited its involvement to the early stages of my PhD. However, in the settings where PPI has been established, in the UK, for example, useful guidelines provide advice on objective assessment of effective PPI involvement. NIHR developed one of
such guidelines, the UK Standards for Public Involvement, allowing researchers to assess whether they have employed PPI adequately in their research [275]. This guideline outlines six overarching standards, each with its own indicators:

i) Inclusive opportunities;

ii) Working together;

iii) Support and learning;

iv) Communications;

v) Impact; and

vi) Governance.

I reflected on these standards in the context of this PhD programme of work (Table 38). Future studies in this setting should consider the involvement of PPI in the early stages of research (e.g., study conceptualisation and design) to narrow power differences between the researcher and the participants.
Table 38 Reflections on Patient and Public Involvement (PPI) in research.

<table>
<thead>
<tr>
<th>UK Standards for Public Involvement</th>
<th>Was this standard achieved in this PhD?</th>
<th>Elaborations</th>
<th>How can I improve this in future work?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inclusive opportunities:</td>
<td>Partially achieved</td>
<td>PPI is a relatively new paradigm in Malaysia. When the study started, PPI was just being established in Malaysia with support from RESPIRE (the NIHR Global Health Research Unit on Respiratory Health), limiting pre-study input in the design. This also limits PPI involvement during the early stage of the PhD’s programme of work.</td>
<td>Consider a more widespread advertisement and transparent opportunities for PPI in the early stages of research (e.g., research proposal writing and funding application) through advertisement in social media, mainstream media or public spaces.</td>
</tr>
</tbody>
</table>
| Working together: Work together in a way that values all contributions and that builds and sustains mutually respectful and productive relationships. | Partially achieved | Although PPI did not feature in the early stages of this PhD, I had the opportunity to redefine PPI involvement in my work when I started my PhD through collaboration with the established PPI group and research fellows of the Asthma UK Centre for Applied Research (AUKCAR).

We worked together to ensure some of my research materials were reviewed, such as infographics on ethical conduct in photo-taking and posters about the study. The PPI member from the AUKCAR gave feedback on my video-based participant information for the qualitative study: [https://www.ed.ac.uk/usher/respire/health-literacy-asthma-malaysia/information-leaflets](https://www.ed.ac.uk/usher/respire/health-literacy-asthma-malaysia/information-leaflets).

At this point, the Malaysian PPI group was established. They provided valuable comments on the video and the voice-overs (in four languages), and they added ideas, including the use of supporting images or figures representing Malaysia's diverse community. In addition, I engaged with patients to comment on the topic guides and pilot the photo-taking activity. |

| One of the standard indicators which I did not systematically address is a joint definition of the purpose of PPI from the outset. This was because the way the involvement was carried out in this programme of work was based on the research needs and not on what PPI could offer. However, such an understanding would facilitate a clear understanding of roles and responsibilities and could potentially result in better planning for how PPI and researchers can work more effectively together. |

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| Support and learning: Offer and promote support and learning that build confidence and skills for public involvement in research. | Not achieved | As a new platform, PPI in Malaysia lacked the support in learning materials and development opportunities to guide PPI members in contributing to research. However, during my study conduct, it was clear that PPI members ‘learned by doing’ about their roles and responsibilities with support from researchers. | More structured training is needed on how PPI members can be involved in research and how researchers could involve PPI in their work. Such training must consider PPI needs and be culturally tailored to local norms. |
| Communications: Use plain language for well-timed and relevant communications, as part of involvement plans and activities. | Partially achieved | I employed dedicated one-on-one meetings to discuss research and sought advice about study conduct in Malaysia. I avoided long emails or texts in favour of a brief overview of the meeting agenda. | More structured communications between researchers and PPI members should be put in place. For example, I used a PPI ‘request form’ [276], outlining my PhD’s overview and indicating the type of help I required from the PPI member of AUKCAR in the early stage of my project. |
| Impact: Seek improvement by identifying and sharing the difference that public involvement makes to research. | Achieved | I met the PPI members to update the project status and presented the impact of PPI involvement in my work. For example, I presented the qualitative study findings and the intervention development phases in the Malaysian stakeholder engagement workshop attended by the Malaysian PPI members, who were optimistic about the study and its findings. In addition, end-of-study presentations and discussions on the study findings provided a broader perspective on the interpretation and implications of the findings. | More regular or scheduled meetings during the course of research projects are required to allow PPI members to provide continuous feedback. |
| Governance: Involve the public in research management, regulation, leadership and decision making. | Not achieved | Although I did not have PPI members involved in managing my funding or the administrative process of the research, RESPIRE at the University of Edinburgh included PPI in their governance. However, as a newly established organisation in Malaysia, early involvement of PPI in research projects, including my PhD programme of work, was a limitation. | The strengthening of the PPI platform should be supported through awareness campaigns, education and training to enable the patients and public to be empowered and involved in research governance. |
10.3 Interpretation of findings

I have discussed the findings of the individual projects in the respective chapters (Sections 5.5, 6.5, 7.5 and 9.6). Here I will discuss the PhD programme of work as a whole.

Improving the delivery of care for long-term conditions and those with limited health literacy reflects the WHO agenda to narrow the gap in health inequities [34]. Providing inclusive solutions to health inequities is a priority in many public health systems [121,164,277,278]. In this PhD programme of work, the systematic review identified a gap in evidence about the effectiveness of asthma self-management interventions aimed at people with limited health literacy [142]. Specifically, there was a lack of high-quality trials conducted in this area [142], which is of concern as health literacy is a problem globally, especially in LMICs. Previous reviews have not focused on asthma, are out of date [87] or used low socioeconomic status as a surrogate marker for limited health literacy [86].

The lack of such trials highlighted how asthma is often overlooked from the health policy point of view compared to other non-communicable diseases [279,280]. In Malaysia, for example, the recent National Health and Morbidity survey did not include the burden of asthma in its report [94], and the last time it was reported was in 2006 [95]. This may affect the quality of care provided to people with asthma in general and further exacerbate problems for people with limited health literacy, who are already at risk of not receiving adequate and effective care for their asthma [49,221]. Thus, an intervention aimed at people with limited health literacy to support asthma self-management needs to be developed and assessed for effectiveness.

Before an intervention can be developed, there is a need to understand the needs and challenges of living with asthma among people with limited health literacy. Limited health literacy is associated with a range of socio-demographic characteristics, but it tends to disproportionately affect vulnerable populations and inevitably perpetuates health inequalities [49]. The narrative
analysis of the qualitative data echoed this statement and revealed challenges around the negotiation of identity, social expectations and stigma. These findings highlight the unmet needs of people living with asthma within the complex social structures and economic systems that overlap with individual health literacy. To add to that, my framework analysis highlighted that health literacy is socially constructed and that instilling knowledge about asthma must make sense in people’s lives. It reported (Section 7.4.2) how socio-cultural aspects and experiential knowledge affected understanding about asthma among participants in this study and influenced how they managed their asthma [179]. People living with chronic illnesses, such as asthma, may interpret their problems differently depending on health beliefs and experiences [76, 281]. Social norms and culturally determined health practices may reflect underlying cultural meanings, values and power systems in various community groups in a population [281]. For example, the decisions of participants in this study to use complementary and alternative medicine were influenced by deeply established social norms within a community and, more often than not, emulated the practice of a dominant figure within their social structure [179]. Health practices that deviate from such norms and standards may be stigmatised. Thus, effectively incorporating self-management knowledge and strategies requires explicit understanding and adaptations to suit cultural meanings and values.

Improving health literacy aims to enable people to take a more active role in managing their own health, engage more effectively in community actions, and exert influence on leaders to advocate policies that can narrow the gap in health disparities. Echoing the WHO stand on digital technologies in health as a tool to promote health and serve the vulnerable [282], and the exercise I undertook in Section 8.2 using the 6SQuID model, I developed a prototype mobile app to support asthma self-management aimed at people with limited health literacy. There are a few health literacy interventions delivered digitally or through innovative approaches in LMICs, but none use mobile Apps [283].
Digitalisation in health is inevitable, especially since the pandemic has accelerated its use for diagnostic purposes, surveillance and information sharing. However, stakeholders must acknowledge the unintended consequences of digital technologies, which include discrimination, privacy breaches, misinformation and cyber-attacks. Azzopardi-Muscat and Sørensen propose the health literacy approach as a possible avenue to ensure that digital technologies work to reduce rather than reproduce health inequalities [284]. Reflecting on this call [284], my Design Sprint workshop included the targeted population (people with asthma and limited health literacy) early in the app development process [112]. As described in Section 9.5, I included strategies to address participants’ need for understanding asthma and support for self-management (e.g., a pictorial asthma action plan and signposting to reliable sources of information about asthma).

This PhD programme of work has demonstrated the development of an asthma self-management app to support people with limited health literacy by incorporating international and local evidence. Targeting evidence-based treatment and asthma self-management support for marginalised populations (specifically, people with limited health literacy) may support the delivery of equitable care and address social deprivation while closing the gap in health inequality. Engaging in technology to deliver supported asthma self-management strategies is timely, reflecting the social response to the global pandemic and the opportunities presented by this information age [238,285], especially with the advent of 5G technology. A feasibility study for the prototype app which I developed is now required. If this is promising, formal evaluation (e.g., in an RCT) would be needed before it can be extensively implemented to support self-management.

10.3.1 Insights for the RESPIRE asthma improvement work and potential for further research

In Section 1.1, I described where my PhD programme of work fits into the broader context of RESPIRE programme of work in Malaysia. While RESPIRE focuses on improving asthma care for patients (adults [286] and children
[79,287,288]), healthcare professionals [243] and organisations, my PhD research has focused on people with limited health literacy, the findings of which feed into the RESPIRE programme.

Being part of a wider research agenda has enabled me to understand the research problems and see them from a broader perspective. This provides an opportunity for me to incorporate the lessons of the RESPIRE programme into my work. For example, from a project interviewing healthcare professionals, I learned that asthma action plans are not readily available in health settings, making it difficult to prescribe one for the patient [243]. Thus, having an asthma action plan on a patient’s mobile phone, a commonly used device, allows the patient to actively take responsibility for their health and have the plan with them during a consultation to assist discussion about self-management.

One focus of RESPIRE is developing and evaluating interventions at the patient level to improve asthma care. My findings provide insight into the understanding of asthma and the need to support self-management from the perspectives of people with limited health literacy. The shared learnings enabled more inclusive solutions and interventions for people living with asthma in this setting. The overall programme of work provides an environment for me to continue the work to the next stage through, for example, RESPIRE-2 or other local or global health funding.

10.3.2 Stakeholder engagement: raising awareness in a local and global community

Giving voice to those unheard

Putting the focusing on communities is the strength of Photovoice, with expectations for it to provide a platform for policy influence and community engagement [289]. In terms of policy influence, my photography exhibition went beyond the local community to influence national stakeholders in Malaysia. For a recap (Section 6.4.1), I arranged a small-scale exhibition at a scientific meeting conducted in Malaysia attended by all colleagues from the RESPIRE Global Unit. The stakeholders included influential and senior
government personnel in Malaysia, such as the Deputy Minister of Health and the Deputy Director General of Health. I stood with a participant who had agreed to participate in the exhibition, to interact with the stakeholders (Figure 51a). An accompanying booklet (Figure 51b, available from https://www.ed.ac.uk/usher/respire/phd-studentships/hani-salim) was created to explain the photographs being exhibited, which helped the participant responded to questions about photographs that did not belong to her. Despite her initial concerns (e.g., anxiety at meeting with stakeholders), the exhibition was a success, and the participant enjoyed the experience of representing the voices of people living with asthma. Building on this experience, future events should support participants in presenting their photographs and communicating their ideas to the public. Formal training for such a public exhibition may help give confidence to people for whom this is a new experience.

**Figure 51 Photovoice exhibition at RESPIRE’s Annual Scientific Meeting.**

<table>
<thead>
<tr>
<th>a. The participant at the event (Mrs Hanum, extreme left)</th>
<th>b. The accompanying booklet</th>
</tr>
</thead>
</table>

Footnote: This photograph was included with permission from Mrs Hanum and Professor Hilary Pinnock.
In an age of global collaboration and the internet, my idea of ‘community’ is not geographically limited. I also recognised the importance of promoting the community voice, and thus the photographs from this study have been used within the global community, although not in a traditional local photography exhibition. Apart from featuring in the face-to-face event, some of the photographs and findings were featured via abstract publications ([https://www.ipcrq.org/11571](https://www.ipcrq.org/11571)), the RESPIRE website ([https://www.ed.ac.uk/usher/respire/news/2021/world-asthma-day-photovoice-experiences-malaysia](https://www.ed.ac.uk/usher/respire/news/2021/world-asthma-day-photovoice-experiences-malaysia)) and an online photo-exhibition as part of a project by the Centre for Biomedicine, Self and Society’s Visualising Bodies programme of events in the UK Being Human Festival ([https://capturing-chronic-illness.com/](https://capturing-chronic-illness.com/)) to represent the global community of people living with asthma and limited health literacy. It is our observation that this process, a 21st-century adaptation of the Photovoice concept, has given ‘voice’ to this global community – and we hope this voice will be increasingly heard as a number of colleagues in the RESPIRE collaboration are planning similar Photovoice projects as part of a RESPIRE renewal application. This work was featured on the NIHR Global Health network to celebrate World Asthma Day 2021 ([https://twitter.com/RESPIREGlobal/status/1389495266743627781/retweets/with_comments](https://twitter.com/RESPIREGlobal/status/1389495266743627781/retweets/with_comments)). The British High Commission in Kuala Lumpur has picked up the publication from the Photovoice work [179] (Facebook: [https://fb.watch/ad_SuhbLMG/](https://fb.watch/ad_SuhbLMG/) and Twitter: [https://twitter.com/UKinMalaysia/status/1466316207263559683](https://twitter.com/UKinMalaysia/status/1466316207263559683)). I am currently working on a short video that will be published on the British High Commission’s social media channel to share information about the research and its implications for patients and practices. Using 21st-century dissemination technologies and strategies, the voice of the global community of people living with asthma who have limited health literacy could be represented. My adaptation of community awareness with global awareness enabled by digital communication is new in the Photovoice literature [174,177,289].
Promoting digital health

I demonstrated the mobile app prototype at local healthcare practices attended by healthcare professionals, such as nurses and pharmacists, and I collaborated on creating a video about the app (https://www.youtube.com/watch?v=MVN_ET5WIDE). I was also one of the panellists for a webinar entitled ‘Is Malaysia ready for a digital transformation in healthcare?’, where I presented on the development of mobile technology to deliver pictorial asthma action plans and other asthma self-management strategies (Appendix 25 for the webinar’s poster). Discussions generated from these dissemination events helped me obtain a broader perspective of my findings. The outcome of the discussion included developing video-based health information about asthma. This video’s inclusive aspect will feature voice-overs of the information using common languages used in Malaysia, diverse characters, and an embedded sign language about the information. The suggestion to include sign language was shared with me by a PPI member who knew a person living with asthma in Malaysia who finds it difficult to find information about asthma in sign language. I am currently involved in scoping work by a RESPIRE colleague to explore the information technology infrastructure available in different countries. The idea of this scoping work is to understand the potential for digital interventions for the RESPIRE partners and to provide stakeholders with practical recommendations on how to implement digital health interventions in low-resource settings by optimising existing infrastructures.

10.4 Implications and recommendations

10.4.1 Implications for patients

- This PhD programme is a step forward in raising awareness of limited health literacy and its impact on asthma patients. A greater understanding of this issue at all levels could drive initiatives to improve patient’s access to health information and services, including disease prevention.
- Tailoring asthma information to patient’s health literacy needs may enhance comprehension of asthma and how to manage it.
• Using a daily gadget (in this case, a mobile app) to provide personalised support for asthma self-management may help to promote an evidence-based norm in asthma management.

10.4.2 Implications for policymakers

• Health literacy is a marker of broader life circumstances such as poverty and limited access to education [49]. There is a need to strengthen national policies on literacy and health literacy in the context of education as well as funding social care services. The WHO has highlighted the importance of addressing health literacy throughout life course interventions (e.g. in schools and during adulthood) which could improve health literacy and potentially reduce health and social inequalities [34].

• Digital technology in health has the potential to bridge health inequalities through inclusive implementation. However, to integrate digital innovation with public health goals, suitable policies and effective governance frameworks are required [284,290]. For example, establishing a policy environment that encourages and drives industry to develop, adopt and employ technologies that support public health system goals [291]. Specifically, one of the challenges lies in policy supporting digital transformation in healthcare and funding for affordable infrastructure to support digital health uptakes, such as internet coverage and data plans.

• The app developed in this study does not need to go through any legislative process in Malaysia [259]. However, such legislation is essential to ensure patients’ safety and privacy in using technology to manage their health. In the absence of such regulations in Malaysia, policymakers in the field of digital health in Malaysia must prioritise discussions among key stakeholders, such as healthcare professionals, patients, app developers and lawmakers. This discussion is an essential step in developing a guideline for using technology in healthcare to protect patient safety and support the rapidly changing field of technology-based research.
10.4.3 Implications for healthcare providers and clinical practice

Doctor–patient communication

- There is a need to implement strategies to ensure that all healthcare providers are aware of patients’ health literacy needs and are skilled in health literacy tools, such as the teach-back methods, motivational interviewing and non-stigmatising communication techniques [230,277]. Effective doctor–patient communication and relationship has been shown to improve the therapeutic relationship and health outcomes through factors, such as better understanding of health conditions and their management [57,58].

Catering to health literacy needs

- Practices should consider the availability of culturally tailored and linguistically appropriate asthma information, alternative formats to the written version (e.g., pictorial-based health information) or support for translators in the health system, as these options have been shown to increase the accessibility of the health service and improve health outcomes [121,208-210,277,292].
- Employing teamwork to provide tailored asthma education and training for patients based on their literacy needs, including trained lay health workers, may offer an advantage to support and sustain a structured and tailored patient education programme [5,121].

10.4.4 Implications for research

Health literacy: a social practice

- A participatory approach may be suitable for co-designing interventions to address local health literacy needs, so that the solutions are practical and suitable to match the population’s socio-cultural needs [293].
- The attempt to describe and understand the lived experiences of people living with asthma and limited health literacy at a particular time point hint
at, but do not do justice to, the multi-layered obstacles that people encounter and struggle to cope with daily. A social-anthropological research design may render a more explicit understanding of how social norms and culturally determined health practices are stratified within and between multicultural communities.

Health literacy tailored self-management app to deliver asthma care

- The app prototype that was developed for people with limited health literacy to support self-management has the potential to improve asthma control but COVID-delays meant this could not be conducted within the PhD. The proposal to assess the app prototype feasibility, including estimation on the clinical outcome is in Appendix 26. The feasibility study is needed to inform a future trial.
- The app prototype was developed in Bahasa Malaysia language. Future research will involve translating the app content to other common languages used in Malaysia, such as Tamil and Mandarin.
- Digital health intervention may not apply to all; for example, those with limited access to the internet or a power supply may not be able to engage with it. Other methods or formats may be needed in more rural settings; thus, a future study should explore the system and population readiness for digital health transformation in Malaysia.

Research methodology

- The Photovoice methodology and its findings have sparked interest in its use in partner countries as part of the RESPIRE-2 programme. The proposed work is a component of a programme of work in RESPIRE looking at estimating the chronic respiratory disease (asthma and COPD) burden in adults in Asian LMICs (4CCORD). (Link: Estimating chronic respiratory disease burden | The University of Edinburgh). Learning from my Photovoice study can be adapted for other cultures and contexts.
10.5 Conclusion

The objectives for this PhD, the projects I undertook to fulfil the objectives, and my key findings and conclusions are summarised in Table 39.
Table 39 Conclusions from this PhD programme of work.

<table>
<thead>
<tr>
<th>PhD Objectives</th>
<th>Methods</th>
<th>Conclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1a To evaluate the clinical effectiveness of asthma self-management interventions aimed at individuals with limited health literacy</td>
<td>Systematic review</td>
<td>The paucity of studies and diversity of the interventions to support people with limited health literacy to self-manage their asthma meant that the impact on health outcomes remains unclear, thus emphasising the need to build such an intervention.</td>
</tr>
<tr>
<td>1b To identify the behaviour change strategies used in the interventions associated with effective programmes</td>
<td>Systematic review</td>
<td>The development of intervention may require theoretical soundness, necessitating the usage of a framework to inform its development. Based on the Behaviour Change Wheel framework, intervention functions that were not used in included studies represented gaps that could be utilised in future interventions. Involving stakeholders, particularly end-users such as patients, at the intervention development stage has the ability to enhance uptake and make the intervention more applicable to solving real-world problems.</td>
</tr>
<tr>
<td></td>
<td>To explore their stories about living with asthma among people with limited health literacy in Malaysia</td>
<td>Adapted Photovoice study</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>2b</td>
<td>To explore the role of health literacy in understanding asthma and how it influences self-management decisions.</td>
<td>Adapted Photovoice study</td>
</tr>
<tr>
<td>2c</td>
<td>To identify barriers to using evidence-based self-management plans among people with limited health literacy and to identify how the use of such plans can be supported</td>
<td>Adapted Photovoice study</td>
</tr>
<tr>
<td>3</td>
<td>To design an intervention underpinned by a theory of change</td>
<td>Theory of change: mechanism of impact</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>4a</td>
<td>To optimise user experience in prototype development by integrating patients and health professionals in the process</td>
<td>Design Sprint method</td>
</tr>
<tr>
<td>4b</td>
<td>To model key aspects of the prototype and test to identify utility and usability issues</td>
<td>Design Sprint method</td>
</tr>
<tr>
<td>4c</td>
<td>To refine and develop the prototype app</td>
<td>Design Sprint method</td>
</tr>
</tbody>
</table>
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Appendices

Appendix 1 Ethical approval from the Medical Research and Ethics Committee of the Ministry of Health, Malaysia: ID (NMRR-18-2113-42322)

JAWATANKUASA ETIKA & PENYELIDIKAN PERUBATAN
(Medical Research & Ethics Committee)
KEMENTERIAN KESIHATAN MALAYSIA
da Institi Pengurusan Kesihatan
Jalan Rumah Sakit, Bangsar
50000 Kuala Lumpur

Ruj.Kami : KKM.NIHSEC. P18-1945 (6)
Tarikh : 09-Oktober-2018

DR HANI SYAHIDA BINTI SALIM
THE UNIVERSITY OF EDINBURGH

DR INGRID YOUNG
THE UNIVERSITY OF EDINBURGH

DR HILARY PINNOCK
THE UNIVERSITY OF EDINBURGH

DR LEE PING YEIN
UNIVERSITY PUTRA MALAYSIA (UPM)

DR SAZLINA SHARIFF GHAZALI
UNIVERSITY PUTRA MALAYSIA (UPM)

YBhg. Dato' / Tuan / Puan,

SURAT KELULUSAN ETIKA: NMRR-18-2113-42322 (IIR)
THE VIEWS AND EXPERIENCES OF PEOPLE WITH LIMITED HEALTH LITERACY AND ASTHMA ON MANAGING THEIR CONDITION: A QUALITATIVE STUDY

Lokasi Kajian:

KLINIK KESIHATAN BANDAR BOTANIC
KLINIK KESIHATAN BUKIT KUDA
KLINIK KESIHATAN KAPAR
KLINIK KESIHATAN KLANG
KLINIK KESIHATAN MURU
KLINIK KESIHATAN PANDAMARAN
KLINIK KESIHATAN PELABUHAN KLANG
KLINIK KESIHATAN RANTAU PANJANG, KLANG

Dengan hormatnya perkara di atas adalah dirujuk.

2. Jawatankuasa Etika & Penyelidikan Perubatan (JEPP), Kementerian Kesihatan Malaysia (KKM) tiada halangan, dari segi etika, ke atas pelaksanaan kajian tersebut. JEPP mengambil maklum bahawa kajian tersebut hanya melibatkan pengumpulan data melalui:

   i. Temubual
   ii. Gambar foto

[References]
3. Segala rekod dan data subjek adalah SULIT dan hanya digunakan untuk tujuan kajian ini dan semua isu serta prosedur mengenai data confidentiality mesti dipatuhi.

4. Kebenaran daripada Pegawai Kesihatan Daerah / Pengarah Hospital dan Ketua-Ketua Jabatan atau pegawai yang bertanggungjawab disetiap lokasi kajian di mana kajian akan dijalankan mesti diperolehi sebelum kajian dijalankan. YBhg. Dato’ / Tuan/ Puan perlu akur dan mematuhi keputusan tersebut. Sila rujuk kepada garis panduan Institut Kesihatan Negara mengenai penyelidikan di institusi dan fasiliti Kementerian Kesihatan Malaysia (Pindaan 01/2015) serta lampiran Appendix 5 untuk templet surat memohon kebenaran tersebut.


   i. **Continuing Review Form** selewat-lewatnya dalam tempoh 1 bulan (30 hari) sebelum tamat tempoh kelulusan ini bagi memperbaharui kelulusan etika.

   ii. **Study Final Report** pada penghujung kajian.

   iii. Mendapat kelulusan etika sekiranya terdapat pindaan ke atas sebarang dokumen kajian / lokasi kajian / penyelidik.

6. Sila ambil maklum bahawa sebarang urusan surat-menyurat berkaitan dengan penyelidikan ini haruslah dinyatakan nombor rujukan surat ini untuk melancarkan urusan yang berkaitan.

Sekian terima kasih.

"BERKHIDMAT UNTUK NEGARA"

Saya yang menjalankan amanah,

(DRAJIR SALINA ABDUL AZIZ)
Pengerusi
Jawatankuasa Etika & Penyelidikan Perubatan
Kementerian Kesihatan Malaysia
mrecsec@nih.gov.my
03-2282 9085

s.k.: HRRC Hospital Tuanku Ampuan Rahimah

Hz/Approval2018/Mrecshare
Appendix 2 Sponsorship approval from the Academic and Clinical Central Office for Research & Development at the University of Edinburgh (ACCORD) (ID: AC18113)

25th January 2019

Dear Prof Sheikh,

Study Title: The views and experiences of people with limited health literacy and asthma on managing their condition: a qualitative study

The University of Edinburgh agrees in principle to act as Sponsor for this project.

Sponsorship is subject to you receiving a favourable ethical opinion from an authorised ethics committee in the countries involved in the study, if required.

Our Sponsor review has determined the project to be low risk and we confirm that a UK based ethical opinion is not required.

As Chief Investigator, you must ensure that the study does not commence until all applicable approvals have been obtained. Following receipt of all relevant approvals, you should ensure that any substantial amendments are reviewed and authorised by the Sponsor prior to submission for applicable approvals.

Yours sincerely,

Chris Conner
Research Governance Coordinator
University of Edinburgh
The Queen’s Medical Research Institute
47 Little France Crescent
Edinburgh, EH16 4TJ
Appendix 3 Ethical approval from the Medical Research and Ethics Committee of the Ministry of Health, Malaysia: ID (NMRR-19-3609-52292)

Dear Dato/ Dr/ Sir/ Madam,

LETTER OF ETHICAL APPROVAL:

NMRR-19-3609-52292 (IR)
DEVELOPING, REFINING AND FEASIBILITY STUDY OF A PICTORIAL ASTHMA ACTION PLAN MOBILE APPLICATION FOR PEOPLE WITH LIMITED HEALTH LITERACY IN MALAYSIA (M-PAAP)

This letter is made in reference to the matter above.

2. The Medical Research and Ethics Committee (MREC), Ministry of Health Malaysia (MOH) has provided ethical approval for this study. Please take note that all records and data are to be kept strictly CONFIDENTIAL and can only be used for the purpose of this study. All precautions are be taken to maintain data confidentiality. Permission from the District Health Officer / Hospital Administrator/ Hospital Director and all relevant heads of departments/funds where the study will be carried out must be obtained prior to the study. You are required to follow and comply with their decision and all other relevant regulations including the Access to the Biological and Benefit Sharing Act 2017.

3. The investigators and sites involved in this study are:

   Klinik Kesihatan Bendar Botani
   Dr Hani Syahida Binti Salim (Principal / Coordinating Investigator)
   Dr ingrid Young
   Dr Lee Ping Yean
   Dr Sazlina Shariff Ghazali
   Hillary Pinnock

4. The following study documents have been received and reviewed with reference to the above study:

   Documents received and reviewed with reference to the above study:
   1. Cover letter to MREC (Version 2, dated 17-01-2020)
   2. Declaration of Conflict of Interest (COI) (Version 1, dated 30-12-2019)
   6. Questionnaire (Version 1, dated 30-12-2019)
   7. Data Collection Form (Version 1, dated 30-12-2019)

.../2...

[References]
Ref: KKM/NIHSEC/P20-10(11)

9. IA-HOD-I, CV and GCP Certification of:
   - Dr Hani Syahida Binti Salim
   - Dr Lee Ping Yein
   - Dr Szalina Shariff Ghazali
   - Hilary Pinnock

10. IA-HOD-I and CV of:
   - Dr Ingrid Young

5. Please note that the approval is valid until 19-January-2021. The following are to be reported upon receiving ethical approval. Required forms can be obtained from the Medical Research Ethics Committee (MREC) website (http://www.nih.gov.mv/mrec).

   i. Continuing Review Form has to be submitted to MREC within 2 months (60 days) prior to the expiry of ethical approval.

   ii. Study Final Report upon study completion to the MREC.

   iii. Ethical approval is required in the case of amendments/changes to the study documents/study sites/study team. MREC reserves the right to withdraw ethical approval if changes to study documents are not completely declared.

   iv. Applicable for Clinical Interventional Studies only: Report occurrences of all Serious Adverse Events (SAEs), Suspected Unexpected Serious Adverse Reaction (SUSARs) and Protocol Deviation/Violation at all MREC approved sites to MREC. SAEs are to be reported within 15 calendar days from awareness of event by investigator. Initial report of SUSARs are to be reported as soon as possible but not later than 7 calendar days from awareness of event by investigator, followed by a complete report within 8 additional calendar days.

6. There will be 55 subjects/patients/respondents targeted to be enrolled in this study within Malaysia.

7. Please take note that the reference number of this letter must be stated in all future correspondence related to this study to facilitate the administrative processes.

Project Sites:

KLINIK KESIHATAN BANDAR BOTANIK

Decision by Medical Research & Ethics Committee:
(✓) Approved
(  ) Disapproved

Date of Approval: 20-June-2019

DR. HIJjasALINA BINTI ABDUL AZIZ
Chairperson
Medical Research & Ethics Committee
Ministry of Health Malaysia
(MMC No: 27117)

C.C:

HRRC Hospital Tengku Ampuan Rahimah

CMMREC_Share/Approval 2020/Expeditied by Primary Reviewer January 2020/52292

-2-
Appendix 4: Sponsorship approval for the development phase by the Academic and Clinical Central Office for Research & Development (ACCORD) at the University of Edinburgh (ID: AC20011)

3rd March 2020

Dear Prof Sheikh,

Study Title: Developing, refining and feasibility study of a pictorial asthma action plan mobile application for people with limited health literacy in Malaysia (m-PAAP)

Sponsor number: AC20011

The University of Edinburgh agrees in principle to act as Sponsor for this project subject to the following conditions:

**Phase 1 can commence once:**
- All appropriate local approvals have been obtained and the sponsor is in receipt of the approval letters.
- Insurance cover has been confirmed by the University of Edinburgh insurance office.

**Phase 2 can commence once:**
- All appropriate local approvals have been obtained and the sponsor is in receipt of the approval letters.
- Insurance cover has been confirmed by the University of Edinburgh insurance office.
- The study has study has received a UK based ethical opinion.
- A separate communication from the Sponsor ("Sponsor Authorisation to Open") will follow once the Sponsor is satisfied that the aforementioned actions have been implemented.

As Chief Investigator, you must ensure that the study does not commence until all applicable approvals have been obtained. Following receipt of all relevant approvals, you should ensure that any amendments are reviewed and authorised by the Sponsor prior to submission for applicable approvals.

Yours sincerely,

The University of Edinburgh is a charitable body, registered in Scotland, with registration number SC014991.
Appendix 5 Amendment approval from the Medical Research and Ethics Committee of the Ministry of Health, Malaysia (ID: NMRR-19-3609-52292)

JAWATANKUASA ETIKA & PENYELIDIKAN PERUBATAN
(Medical Research & Ethics Committee)
KEMENTERIAN KESIHATAN MALAYSIA
d/a Kompleks Institut Kesihatan Negara
Blok A, No 1, Jalan Setia Murni U13/52
Seckeyn U13, Bandar Setia Alam,
40170 Shah Alam, Selangor.

Ref.: KKM/NIHSEC/ P20-10 (13)
Date: 17-June-2020

DR HANI SYAHIDA BINTI SALIM
THE UNIVERSITY OF EDINBURGH

DR INGRID YOUNG
THE UNIVERSITY OF EDINBURGH

HILARY PINNICK
THE UNIVERSITY OF EDINBURGH

DR LEE PING YEIN
UNIVERSITY PUTRA MALAYSIA (UPM)

DR SAZLINA SHARIF GHAZALI
UNIVERSITY PUTRA MALAYSIA (UPM)

Dear Sir/Mdm,

AMENDMENTS FOR STUDY: NMRR-19-3609-52292 (IIIR)
Protocol No:
Developing, refining and feasibility study of a pictorial asthma action plan mobile application for people with limited health literacy in Malaysia (m-PAAP)

Your amendment submission dated 16-June-2020 is referred.

2. Amendments of the following have been received and reviewed with reference to the above study:

Documents received and reviewed with reference to the above study:

1. Study Proposal version 3, dated 16 June 2020
2. Patient Information Sheets and Consent form (English & Malay),
   a. English
      i. Doc 1 (version 3, dated 1 May 2020): Participant information sheet and consent form (feasibility study:Phase 1_patient)
      iii. Doc 3 (version 3, dated 1 May 2020): Participant information sheet and consent form (feasibility study:Phase 1_HCP)
   b. Malay
      i. Doc 1 (version 3, dated 1 May 2020): Riasah maklumat peserta dan borang persetujuan (Kajian feasibiliti: Fasa1_Pesakit)

iii. Doc 3 (version 3, dated 1 May 2020): Risalah maklumat peserta dan borang persetujuan (Kajian feasibiliti: Fasa1_Pegawai Kesihatan)


The Medical Research & Ethics Committee, Ministry of Health Malaysia operates in accordance to the International Council for Harmonization of Technical Requirement for Pharmaceutical for Human Use (ICH) and Malaysia Guideline for Good Clinical Practice

Comments (if any): NIL

Decision by Medical Research & Ethics Committee:

( ✓ ) Approved
(   ) Disapproved

Date of Decision: 17-June-2020

DR HJH SALINA BT ABDUL AZIZ
Chairperson
Medical Research & Ethics Committee
Ministry of Health Malaysia
Appendix 6 Examples of posters presented at various conferences and scientific meetings

Poster Title: Developing and piloting an ICT-based intervention for adult asthma with limited health literacy to improve asthma self-management: A RESPIRE PhD.

Event:
2. RESPIRE Annual Scientific Meeting, Porto. May 2018.

Background:
- 95% of present Malaysian asthma population has unmet health literacy.
- 60% of people with asthma has limited health literacy.
- Ineffective health literacy can lead to poorer adherence to self-management practices and poor clinical outcomes.
- Asthma control remains poor and that they require assistance or no medication on their survival and treatment plans.
- Poor self-management deteriorates asthma control and impacts quality of life.

Research question:
Does an information and communication technology (ICT)-based intervention that address health literacy needs improve self-management among people with asthma?

Methods:
- To ensure high quality results from this project, the NRC framework for the design and evaluation of complex interventions will be used.

Questions to discuss:
1. Are there any suggestions about ICT-based self-management interventions that may be effective in this group?
2. We have three cultural languages in Malaysia. Should I focus on one or include all three?
Poster Title: Addressing linguistic needs in a multilingual population to improve patient's recruitment and understanding of involvement in asthma research.

Poster Title: The psychosocial influence on asthma self-management and health outcomes among people with limited health literacy in Malaysia: A preliminary analysis of an arts-based qualitative study.


The psychosocial influence on asthma self-management and health outcomes among people with limited health literacy in Malaysia: A preliminary analysis of an arts-based qualitative study

H.Salim1,2, Sazilina.SG2, PK.Lee2, J.Young1, H.Pinnock1
1University of Edinburgh, 2Universiti Putra Malaysia

Low health literacy is associated with poor adherence to self-management activities and poor clinical outcomes.

Asthma self-management research needs to tackle, which can be challenging, people with limited health literacy.

Aim

We aimed to explore the views and experiences of people with asthma and limited health literacy on managing their condition using arts-based methodology.

SOCIAL ROLES

"I'm a mother. If I needed to be admitted to the ward, then how about the kids? It's not easy when people ask you to do check up here, do this there, attend follow up..."

IDI 20: 37-year-old, Malay, female

Themes

Religion

Social roles

PHOTOVOICE is an arts-based qualitative method which allows further understanding of these psychosocial aspects among people with limited health literacy in a multicultural society

Context-specific psychosocial factors influence asthma self-management practices and control.

References
Poster Title: Do interventions that address health literacy needs improve self-management among people with asthma? A systematic review.

Poster Title: Negotiating identity: impact on asthma self-management practices in people with asthma and limited health literacy in Malaysia.


Negotiating identity: impact on self-management practices in people with asthma and limited health literacy in Malaysia.

H. Salim1, J. Young1, Satlin. SG2, P. Y. Lee3, H. Finsch3
1 University of Edinburgh, 2Universiti Putra Malaysia

Limited health literacy is associated with poor adherence to self-management activities and poor clinical outcomes.

Adjusting to life with a chronic condition is particularly challenging for people with limited health literacy

AIM

We aimed to explore the views and experiences of people with asthma and limited health literacy on managing their condition using mixed qualitative and arts-based methodology, Photovoice.

RESULTS

FACTORS AFFECTING NEGOTIATION OF IDENTITY

Community
Social support

Family & friends
Stigmatising experiences

Individuals
Poor understanding of asthma and its management

ASTHMA DIAGNOSIS

Acceptance
Non-acceptance

IMPACT ON SELF-MANAGEMENT PRACTICES

As a single mother, the money [financial aid] helps. I don't have to work 3 jobs and my asthma was better when I have time to use the inhalers everyday.

'I feel embarrassed. I will go to the toilet if I want to use this.'

'I don't know that [asthma action plan]. I don't want anything that says I have asthma, especially that plan.'

CONCLUSION

Multi-level awareness and support for people with limited health literacy may help them adopt a strong sense of identity, cope with the demands of living with asthma and potentially lessen stigma.

www.ed.ac.uk/usher/respire
@RESPIREGlobal

NIHR funded research in health and care. The views expressed are those of the author and not necessarily those of the NHS, NHSE or NIHR.

[References]

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Appendix 7 The systematic review protocol published in NPJ Primary Care Respiratory Medicine

Protocol for a systematic review of interventions addressing health literacy to improve asthma self-management

Hari Saling1,2, Ingrid Young3, Sazlina Shariif Ghazali4, Ping Yean Lee4, Siti Noraminah Ramdien1,4 and Hilary Pincock1

INTRODUCTION

Supported self-management for asthma (written action plans and regular review) is highly effective at improving control and reducing acute attacks; however, globally this is challenging to implement both in adults and children. One particular challenge is the need to tailor support for people with limited health literacy.

Limited health literacy is a universal problem, especially (but not only) in low- and middle-income countries (LMICs). For example, nearly 50% of adults with type 2 diabetes attending primary care clinics in Malaysia were assessed as having limited health literacy compared to about half the general population in a European survey. Use of different assessment techniques and sampling of different populations make it difficult to compare these results, though it is clear that this is a problem in all countries.

Derived from a systematic content analysis of 19 papers, Sørensen et al. describes health literacy as people's knowledge, motivation and competence to assess, understand, appraise and apply health information (see Table 1 for definitions). These processes are vital to enable people to make considered judgments and decisions about healthcare and health promotion, which can improve quality of life and health outcomes such as reducing morbidity, mortality.

Health literacy is linked to functional literacy skills such as the ability to read and count. Among people with asthma for example, difficulty in reading is associated with improper use of inhalers and poor disease knowledge. Poor numeracy skills are associated with increased emergency visits and hospitalisations among people with asthma. Studies have also associated limited health literacy with erroneous health beliefs and poor adherence to self-management activities. Without health literacy skills, self-management will be difficult. A review of causal pathways suggests that health literacy is not related to health outcomes in a linear function. Health literacy influenced three aspects of healthcare: (i) access and utilisation of healthcare, (ii) patient-provider interactions, and (iii) self-care. As an example, worsening of symptoms despite initial self-management will motivate people with asthma to seek medical care. However, in people with limited health literacy, poor knowledge of an impending exacerbation may delay early medical attention and result in poor health outcomes.

METHODS

We will follow the procedures described in the Cochrane Handbook for Systematic Reviews of Interventions. The PRISMA-P (Preferred Reporting Items for Systematic reviews and Meta Analyses for Protocols) checklist has been used as a framework for this protocol. The review is registered with the International Prospective Register of Systematic Reviews (PROSPERO): CRD42016116974.

Search strategy

We will search 10 electronic databases listed in Table 2. The search strategy uses medical subject headings (MeSH) and text words related to health literacy, asthma, self-management and controlled trial (Supplementary Table 1). The search will commence from 1990 onwards. Although the term 'health literacy' was introduced in 1995, the concept of asthma self-management was first recommended in the asthma guidelines in 1993.

Reference lists will be examined for other relevant studies, and we will undertake forward citation of any included studies. For unpublished and in-progress studies, we will search the WHO ICTRP World Health

[References]

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Table 1. Definition of terms

<table>
<thead>
<tr>
<th>Terms</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-management</td>
<td>The tasks that individuals must undertake to live with one or more chronic conditions. These tasks include having the confidence to deal with medical management, role management and emotional management of their conditions.</td>
</tr>
<tr>
<td>Health literacy</td>
<td>Health literacy is linked to literacy and entails people's knowledge, motivation, and competencies to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course.</td>
</tr>
<tr>
<td>Severe asthma attacks</td>
<td>Events that require urgent action on the part of the patient and physician (e.g. a course of oral steroids) to prevent a serious outcome, such as hospitalisation or death from asthma.</td>
</tr>
</tbody>
</table>

Table 2. PICOS descriptions and definitions

<table>
<thead>
<tr>
<th>PICOS</th>
<th>Descriptions and definitions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants/population</td>
<td>Participants will be those with physician-diagnosed asthma (children, adolescents, adults, and the elderly) or their parents/caregivers.</td>
</tr>
<tr>
<td>Intervention(s), exposure(s)</td>
<td>Asthma self-management interventions targeted at participants with limited health literacy level will be included. We will note how the authors define limited health literacy and included those interventions that meet our definition (see Table 1). We will also include interventions that include training of healthcare practitioners to give them skills to teach self-management to people with limited health literacy, if the outcomes include the impact on the patient.</td>
</tr>
<tr>
<td>Comparator</td>
<td>Typically, the comparator will be usual care, but may also be alternative self-management strategies, e.g. self-management interventions not targeting health literacy.</td>
</tr>
<tr>
<td>Outcomes</td>
<td>For primary outcomes, we are interested in both health and implementation outcomes. As recommended by the European Respiratory Society/American Thoracic Society (ERS/ATS) Task Force report on asthma outcomes, the primary health outcomes include the following: - Current asthma control (e.g. using a validated questionnaire such as the Asthma Control Questionnaire or Asthma Control Test), - Future risk (e.g. the number of severe attacks, steroid courses, emergency department visits or hospitalisations); we will use the ERS/ATS definition of ‘severe asthma exacerbation’ (see Table 1). The primary implementation outcomes will be the following: adoption of the interventions (e.g. proportion of participants taking up the intervention, provided with an action plan and adherence to interventions (e.g. frequency of usage of an action plan). For secondary outcomes, we will include practical self-management measures such as self-efficacy, activation, empowerment, correct inhaler use, improvement in knowledge, health literacy outcomes and impact indicators of interventions, such as cost-effectiveness, fidelity and sustainability.</td>
</tr>
<tr>
<td>Setting</td>
<td>We will include any clinical or community-based setting. These settings can be based in developed or developing nations (specifically including LMICs).</td>
</tr>
<tr>
<td>Study design</td>
<td>We will include controlled experimental studies: randomised controlled trials (RCTs), controlled clinical trials, controlled before-and-after studies and interrupted time-series designs.</td>
</tr>
</tbody>
</table>
| Database searched              | 1. MEDLINE: Medical Literature  
2. EMBASE: Excerpta Medica database  
3. CINAHL: Cumulative Index to Nursing and Allied Health Literature  
4. PsycINFO: Database of abstracts of literature in the field of psychology  
5. AMED: Allied and Complementary Medicine Database  
6. BNI: British Nursing Index  
7. Cochrane Library: Database of Abstracts of Reviews of Effects, Cochrane Database of Systematic Reviews (CDSR) and Cochrane Central Register of Controlled Trials (CENTRAL)  
8. Web of Science: Core Collection including International Scientific Indexing (ISI Proceedings)  
9. Google Scholar  
10. Global Health                                                                 |

Organization International Clinical Trials Registry Platform: https://www.who.int/trialsearch and US National Institutes of Health Ongoing Trials Register ClinicalTrials.gov: https://www.clinicaltrials.gov for relevant trials and will contact the authors if a publication was not found. We will note any conference abstracts and look for subsequent publications. We will contact experts in the area to enquire about related trials. We do not plan manual searches, unless a query emerged from the electronic searches as focusing specifically in this area. There will be no language restrictions; where possible, we will arrange translation.

Eligibility criteria
We will search the databases using the PICOS criteria and the operational definitions (Tables 2 and 3). We were aware that interventions may not use our chosen terminology, so we will use the definitions in Table 1 to confirm eligibility.

Selection process
The literature search results retrieved from the electronic databases will be uploaded to DistillerSR Software to enable collaboration between reviewers. This software facilitates screening, de-duplication and overall management of the search results. In an initial training process, the two reviewers (H.S. and S.R.K.) will screen a sample of 100 titles and abstracts, compare the results and, in discussion with the study team, refine the inclusion and exclusion criteria. Title and abstract screening will then be undertaken independently by the two reviewers.
Table 3. Operational definitions

<table>
<thead>
<tr>
<th>Terms</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>People with limited health literacy</td>
<td>We defined intervention as one that included people with limited health literacy quantitatively and using evidence-based approaches. Quantitatively, study populations that measured health literacy level using validated tools and included ≥40% of people with limited health literacy in the trial are included. We will include study populations that include individuals with high risk of limited health literacy through publications of evidence in systematic review reports and qualitative studies. This will include the following: 1) immigrants; 2) ethnic minorities; 3) illiterates.</td>
</tr>
<tr>
<td>Types of interventions</td>
<td>(1) Self-management We will include any asthma self-management interventions within the taxonomy of the self-management support components suggested by Taylor et al. 7. a) Direct components (suggested directly to patients and/or carers) such as education, action plans, and practical support with adherence. b) Indirect components: healthcare or social care at a professional level (delivered to individual healthcare professionals or social care professionals such as equipment, feedback and review. c) Indirect components: delivered at an organisational level such as prompts using paper or electronic reminders. (2) Addressing health literacy We will include any interventions that are aimed at improving health literacy as suggested by Sherdan et al. 23: a) Presenting written information differently (e.g., essential information first) b) Presenting numerical information differently (e.g., the highest number is better) c) Using icons, symbols, and graphs d) Preserving information pitched at a lower literacy level (e.g., primary school comprehension) e) Use of videos f) Literacy training for patients and physicians g) Implementing comprehensive skills to enable self-care.</td>
</tr>
</tbody>
</table>

We will obtain the full text of potentially relevant studies, and both reviewers (M.S. and S.N.R.) will independently assess them for eligibility. We will identify and record the reasons for exclusion of ineligible studies. Disagreements or uncertainties at any stage will be resolved by discussion within the team (K.P., K.L., S.G.S., or P.J.L.).

Studies that have multiple publications (e.g., protocol, trial findings, process evaluation, qualitative studies, translations) will be treated as one study; however, reference will be made to the different publications. The process of selection will be summarized using a PRISMA flow diagram to ensure transparency. 22

Data extraction and management

To ensure the quality of description of interventions, we will use the Effective Practice and Organisation Care (EPOC) group recommendations for describing interventions 22 and the Template for Intervention Description and Replication (TIDieR) checklist. 22 Data will be extracted independently by M.S. and S.N.R. into a piloted data extraction form and presented under the following headings: a) Methods: study design, number of study centers and location, study setting, withdrawals, date of study, follow-up.

b) Participants: number, age, gender, severity of condition, inclusion criteria, exclusion criteria, other relevant characteristics.

c) Outcomes: reflecting guidelines recommendations, our primary health outcome was current symptom control and risk of acute attacks. Our primary implementation outcomes are measures of adoption of the intervention. Definitions, methods of assessment and secondary outcomes are as shown in Table 2.

d) Components of the intervention. We will use the behaviour change model to categorize the components of the intervention enabling us to identify strategies associated with effective programmes. 22

To ensure that the tables are interpreted consistently and all relevant data are captured, the two reviewers (M.S. and S.N.R.) will complete the data extraction process and a third reviewer (K.P.) if necessary. We will contact the authors if sufficient information was not found within the included papers.

Assessment of risk of bias in the included studies

All included studies will be assessed independently for potential risk of bias by the two reviewers (M.S. and S.N.R.). We will use the Cochrane Risk of Bias tool 22 and the guidance from the EPOC group 22 to assess selection, performance, detection, attrition, reporting and other potential sources of bias. 22 The risk of bias for each domain will be classified as Low, High, or Unclear based on the information available. 22 We will generate risk of bias summary graphs and figures using Review Manager (RevMan 2012). 22

Assessment of risk of the quality of evidence

We will use the Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach to assess the quality of evidence related to each primary outcome. 22 We will assess the overall quality of evidence for each outcome using five factors: risk of bias, inconsistencies, indirectness, precision of effect estimates, and publication bias. 22 We will down grade the evidence from high quality by one level for serious and by two levels for very serious outcomes (high, moderate, low, very low).

Data analysis

Our data analysis will address the two aspects of our aim (effectiveness and identification of strategies associated with effective programmes).

Analysis of effectiveness of the intervention. We will examine our data for the primary and implementation outcomes to assess their suitability for meta-analysis. For dichotomous outcomes we will use risk ratio (RR) and for continuous outcomes, we will use mean difference (MD). Standardized mean difference (SMD) or mean change difference (MCD). All effect estimates will be presented using 95% confidence intervals (CI).

We will pool data using a random-effects model with the Review Manager (RevMan) 5 software, testing for heterogeneity with Cochran’s Q and I² statistics, and publication bias using Begg’s and Egger’s tests to assess funnel plot asymmetry. 22 Our scope work, however, suggested that studies will vary substantially in design, target populations, outcomes measured and duration of follow-up, so that meta-analysis may not be appropriate. If this is the case, we will undertake a narrative synthesis, potentially illustrating the findings by key outcomes with a Harvest plot. 22
Identification of strategies associated with effective programmes. The second aim will seek to identify the strategies, as described in the Behaviour Change Wheel model, that are associated with effectiveness. The care of this model involves strategies that influence capability, opportunity and motivation, and that result in behaviour change (COM-B). Capability is defined as the individual’s psychological and physical capacity to enact a behaviour. It includes possessing the required knowledge and skills. Motivation is defined as those processes that contribute towards both reflective and automatic mechanisms that activate or inhibit behaviour. Opportunity is defined as aspects of the physical and social environment that lie outside the individual and that prompt or make the behaviour possible. Using the nine intervention functions of the Behaviour Change Wheel, we will map components of the interventions in the included studies to the outcomes. This will enable us to identify components common to successful interventions, to understand the potential mechanisms of action of the interventions, and to also identify gaps around these essential components that govern behaviour system—capability, opportunity and motivation.

**Dissemination**

We will submit the findings of this study to peer-reviewed journals and conference proceedings. Other methods of dissemination will include innovative dissemination channels of **RELIBE** (website and Twitter) to raise awareness of our publications. Apart from formal routes of dissemination, as researchers from various backgrounds, we will use our professional networks, stakeholder engagement activities, and patient and public involvement channels to raise awareness of the work we have done in this area.

**Discussion**

Limited health literacy is associated with erroneous health beliefs, inadequate inhaler technique, limited adherence to self-management activities and sub-optimal clinical outcomes. Although the relationship of health literacy and asthma self-management is likely to be complex, interventions that affect health literacy needs may improve asthma outcomes in this vulnerable population. The findings of the review will inform the development of self-management support interventions targeting people with asthma who have limited health literacy.

**Data Availability**

Data sharing is not applicable. This article is protected by copyright or is the property of the authors. Published with the publisher's permission. Further details can be found in the Acknowledgements section.

**Acknowledgements**

We are grateful to Marshall Dexter, Academic Librarian at the University of Edinburgh, for her help in developing the search strategy. H.S. and S.M.R. are supported by PhD studentships from the **NHRI** Global Health Research Unit on Respiratory Health (**RELIBE**). **RELIBE** is funded by the National Institute of Health Research using Official Development Assistance (ODA) funding. The views expressed are those of the authors and not necessarily those of the NHRI, the NIHR or the Department of Health and Social Care. nestor the funder nor the sponsor (University of Edinburgh) contributed to protocol development.

**Author Contributions**

H.S. and H.P. conceived the idea for this work that was developed with the support of K.C., R.S.S.G., P.L., and S.M.R. S.M.R. wrote the first draft, and all authors contributed to the manuscript.

**Additional Information**

Supplementary information accompanies the paper on the n-pj Respiratory Medicine website. (https://doi.org/10.1093/nph/npy253)

**Conflicts of Interest**

The authors declare no competing interests.

**Publisher's note**

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epi Primary Care Respiratory Medicine (2019) 18

**References**


REFERENCES


Published in partnership with Primary Care Respiratory Society UK.
Appendix 8 The findings from the systematic review were published in the Journal of Global Health

A systematic review of interventions addressing limited health literacy to improve asthma self-management

Hani Salim1,2, Siti Nurkamilia Ramdianz1,2, Sazlina Shariff Ghazali1, Ping Yen Lee1, Ingrid Young1, Hilary McClatchey2, Hilary Pinnock1; on behalf of the NHR Global Health Research Unit on Respiratory Health (RESPIRE) collaborations

1NHR Global Health Research Unit on Respiratory Health (RESPIRE), Usher Institute, The University of Edinburgh, United Kingdom
2Department of Family Medicine, Faculty of Medicine and Health Sciences, Universiti Putra Malaysia, Malaysia
3Department of Primary Care Medicine, Faculty of Medicine, University of Malaya, Malaysia
4Outreach for Respiratory, Self and Society, Usher Institute, The University of Edinburgh, United Kingdom
5Asthma UK Centre for Applied Research, Usher Institute, The University of Edinburgh, United Kingdom

Background: Supported asthma self-management improves health outcomes. However, people with limited health literacy, especially in low-middle-income countries (LMICs), may need tailored interventions to enable them to realize the benefits. We aimed to assess the clinical effectiveness of asthma self-management interventions targeted at people with limited health literacy and to identify strategies associated with effective programmes.

Methods: Following Cochrane methodology, we searched ten databases (January 1990 – June 2018, updated October 2019), without language restriction. We included controlled experimental studies whose interventions targeted health literacy to improve asthma self-management. Selection of papers, extraction of data and quality assessment were done independently by two reviewers. The primary outcomes were clinical (asthma control) and implementation (adoption and adherence to intervention). Analysis was narrative.

Results: We screened 4,318 titles and abstracts, reviewed 52 full-texts and included five trials. One trial was conducted in a LMIC. Risk of bias was low in one trial and high in the other four studies. Clinical outcomes were reported in two trials, both at high risk of bias, one of which reported a reduction in unscheduled care (number of visits in 6-month (SD), Intervention: 0.9 (1.2) vs Control: 1.8 (2.4), P = 0.001); the other showed no effect. None reported uptake or adherence to the intervention. Behavioural change strategies typically focused on improving an individual's psychological and physical capacity to enact behaviour (e.g. targeting asthma-related knowledge or comprehension). Only two interventions also targeted motivation; none sought to improve opportunity. Less than half of the interventions used specific self-management strategies (e.g. written asthma action plan) with tailoring to limited health literacy needs. Different approaches (e.g. video-based and pictorial action plans) were used to provide education.

Conclusions: The paucity of studies and diversity of the interventions to support people with limited health literacy to self-manage their asthma meant that the impact on health outcomes remains unclear. Given the proportion of the global population who have limited health literacy skills, this is a research priority.

Protocol registration: PROSPERO CRD42018118974

[References]
Asthma self-management support, including written action plans and regular reviews by health care professionals, improves health outcomes [1-4]. Systematic reviews and guidelines highlight that cultural or age-related tailoring enables the successful implementation of supported self-management, although rarely specify tailoring for people with limited health literacy. This is a significant oversight, as health literacy is a problem globally [5], and a particular challenge in low and middle-income countries (LMICs). There is thus a need to address the challenges of providing support for people with limited health literacy [6,7].

A review of health literacy definitions by Sørensen et al. (2012), describes health literacy as people’s knowledge, motivation and competence to access, understand, appraise and apply health information to make decisions on health care, disease prevention and health promotion throughout the life course (Table 1) [5]. These skills are essential for individuals to respond to the demands of managing a variable condition such as asthma, including adherence to medication, adjusting treatment and/or deciding to seek advice in the event of deterioration. Health literacy is not linearly related to health outcomes but influences these aspects of health care: access and utilisation of health services, patient-provider interactions and self-management [12].

Two previous systematic reviews have looked at self-management interventions for people with limited health literacy in long-term health conditions [10,13]. One review included 38 studies, but only 2.2 were randomised trials, and none addressed self-management interventions in asthma [10]. The other defined the target population as people from low socio-economic groups, assuming that these populations had limited self-literacy [13]. Neither, therefore, specifically addressed supported management for people with limited health literacy in asthma. We aimed to systematically search and synthesise the trial evidence for asthma self-management interventions targeted at people with limited health literacy, in order to assess their clinical effectiveness and to identify the behaviour change strategies that were associated with effective programmes [1-4].

<table>
<thead>
<tr>
<th>Table 1. Definition of terms</th>
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<tbody>
<tr>
<td><strong>Type</strong></td>
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<tr>
<td>Self-management</td>
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<td>Health literacy</td>
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<tr>
<td>Severe asthma attacks</td>
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</table>
METHODS

This review is registered with the PROSPERO database (registration number: CRD 42018118974). Details of the systematic review protocol have been published [14] with salient points described here. We followed the procedures described in the Cochrane Handbook for Systematic Reviews of Interventions [15].

Deviations from the published protocol

To be inclusive of data from LMICs, we intended to search the African Index Medicus, Africa Portal Digital Library, Index Medicus for the Southwestern Asia Region, IndMed; Latin American and Caribbean Health Science Literature Database (LILACS). However, we decided to omit these after a scoping exercise revealed a lack of controlled trials in these databases, and we considered it was very unlikely that any publications would fulfil our inclusion criteria.

We intended to use the Grading of Recommendations Assessment Development and Evaluation (GRADE) to assess the weight of evidence of the reported outcomes from the included studies [16]. However, there was too much missing information to use GRADE. We have, therefore not presented the GRADE assessment in the paper (see Table S1 in the Online Supplementary Document).

Search strategy

We searched 10 electronic databases (Table 2). The search strategy used medical subject headings (MeSH) and text words related to health literacy, asthma, self-management and controlled trial. The initial search

<table>
<thead>
<tr>
<th>Table 2. PICOS table and operational definitions</th>
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<tbody>
<tr>
<td><strong>PICO</strong></td>
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<tr>
<td><strong>DESCRIPTIONS AND DEFINITIONS</strong></td>
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<tr>
<td><strong>OPERATIONAL DEFINITIONS</strong></td>
</tr>
<tr>
<td><strong>Population</strong></td>
</tr>
<tr>
<td>Physician-diagnosed asthma or their parents/</td>
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<tr>
<td>cases.</td>
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<tr>
<td>Any age: children, adolescent, adults and for</td>
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<td>the elderly:</td>
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<tr>
<td><strong>Intervention</strong></td>
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<tr>
<td>Asthma self-management targeted at patients</td>
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<td>with limited health literacy level, noting</td>
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<tr>
<td>how the authors’ definitions.</td>
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<tr>
<td>We included interventions which trained health</td>
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<tr>
<td>care practitioners to support self-management</td>
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<tr>
<td>in people with limited health literacy if the</td>
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<td>outcomes included the impact on the patient.</td>
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<tr>
<td><strong>Comparator</strong></td>
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<td>Usual care or alternative interventions</td>
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<td>For example: lower intensity self-management</td>
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<td>strategies, or interventions not suggesting</td>
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<td>health literacy.</td>
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<td><strong>Outcomes</strong></td>
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<td>Primary health outcomes.</td>
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<tr>
<td>Asthma control measured by a validated</td>
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<td>questionnaire such as the Asthma Control</td>
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<tr>
<td>Questionnaire [17] or Asthma Control Test [18].</td>
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<tr>
<td>Based on the European Respiratory Society/</td>
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<td>American Thoracic Society ERS/ATS Task Force</td>
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<td>report [11] health outcomes were:</td>
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<tr>
<td>• Current asthma control (eg, control question-</td>
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<tr>
<td>naires).</td>
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<tr>
<td>• Asthma attacks (eg, number of severe attacks,</td>
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<td>delayed courses, emergency department visits,</td>
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<tr>
<td>hospitalisations).</td>
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<tr>
<td>Primary implementation outcomes</td>
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<td>• Adoption of the intervention</td>
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<tr>
<td>• Adherence to intervention</td>
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<tr>
<td>Secondary outcomes</td>
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<tr>
<td>Examples of adoption/adherence included</td>
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<td>proportion of participants taking up the</td>
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<td>intervention, provided with, or frequency of</td>
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<td>usage of an action plan.</td>
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<tr>
<td>Self-efficacy, activation, empowerment, health</td>
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<tr>
<td>literacy.</td>
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<tr>
<td>Improvement in knowledge, Correct inhaler use</td>
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<tr>
<td>Cost-effectiveness, fidelity and sustainability</td>
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<tr>
<td>Setting</td>
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<tr>
<td>Any clinical or community-based setting in any</td>
</tr>
<tr>
<td>country (developed or developing nations)</td>
</tr>
<tr>
<td>Study design</td>
</tr>
<tr>
<td>Controlled experimental studies: Randomised</td>
</tr>
<tr>
<td>controlled trials (RCTs), controlled clinical</td>
</tr>
<tr>
<td>trials, controlled before-and-after studies,</td>
</tr>
<tr>
<td>and interrupted time-series designs</td>
</tr>
<tr>
<td>Database searched</td>
</tr>
<tr>
<td>LIOPAC, REBIS, PIRs, PIRs, AMED, BNI, BMJ</td>
</tr>
<tr>
<td>Cochrane Library, Database of Abstracts of</td>
</tr>
<tr>
<td>Reviews of Effects, Cochrane Database of</td>
</tr>
<tr>
<td>Systematic Reviews (CDSR) and Cochrane Central</td>
</tr>
<tr>
<td>Register of Controlled Trials (CENTRAL), Web of</td>
</tr>
<tr>
<td>Science, Care Collection, ScienceDirect, and</td>
</tr>
<tr>
<td>Global Health.</td>
</tr>
</tbody>
</table>

[References]
(January 1990 to June 2018) was updated in October 2019. We conducted forward citation on included studies and contacted experts in the field to identify related trials. We did not perform manual searches as no journal(s) emerged as having a particular interest in this topic. There was no language restriction, though we did not find any non-English publications. We searched the databases using PICOS criteria (Table 2). We used the definitions in Table 1 to confirm eligibility.

**Study selection and data extraction**

After training and quality control, two authors (HS and SNR) independently screened the de-duplicated titles and abstracts. We obtained the full text of potentially relevant studies, and both reviewers independently assessed for eligibility. Disagreements or uncertainties at any stage were resolved by discussion within the team (HP, RI, SGS or PVL).

Studies which had multiple publications (eg, a protocol, trial findings, process evaluations, qualitative studies, translations) were treated as one study, and reference made to the different publications.

We piloted a data extraction form adapted from the Effective Practice and Organisation of Care (EPOC) recommendations for describing interventions [19] and the Template for Intervention Description and Replication (TIDieR) checklists [20]. Two reviewers (HS and SNR) independently extracted data. We contacted authors for any information which was not found within the included paper(s).

**Quality assessment**

We used the Cochrane Risk of Bias tool [15], and the guidance from the EPOC group [19], to assess selection, performance, detection, attrition, reporting and other potential sources of bias [15]. The risk of bias for each domain was classified as low, high, or unclear based on the information available [15]. We generated 'risk of bias' summary graphs and figures using Review Manager 5.3 [21].

**Outcomes**

Outcomes are described in Table 2. We were primarily interested in health outcomes (eg, asthma control, acute attacks) and implementation outcomes (eg, adoption of intervention). Secondary outcomes included intermediate self-management measures (eg, knowledge, improvement), health literacy outcomes and impact indicators (eg, cost-effectiveness).

**Data synthesis.**

We conducted two analyses to answer the two objectives of our systematic review. First, we considered the effectiveness of asthma self-management interventions which addressed health literacy needs compared with the control group. From scoping work, we anticipated that the studies included in this review would vary substantially in design, target populations, outcomes measured and duration of follow-up precluding meta-analysis. We, therefore, conducted a narrative synthesis of the data.

Second, we described and characterised the included interventions using the behaviour Change Wheel (BCW) framework (Figure 1), which provides a systematic way to describe and characterise the techniques used in the interventions in this review [22,23]. The BCW has three layers, its core components consist of the COM-B system (Capability, Opportunity and Motivation). Interactions between these components determine Behaviour [22]. Capability is the individual's psychological and physical capacity to engage in the behaviour. It includes having the required knowledge and skills. Motivation is defined as processes that contribute towards both reflective and automatic mechanisms that activate or inhibit behaviour. Opportunity includes aspects of the physical and social environment that lie outside the individual that prompt or make behaviour possible. The second layer of the BCW describes the nine functions of interventions that are designed to change behaviour. The intervention
functions are: education, persuasion, coercion, training, enablement, modelling, environmental restructuring, and restrictions. The third layer of the BCW identifies seven types of policies (eg, legislation, fiscal measures, etc.) that can be applied to deliver these intervention functions [22].

It is proposed that specific intervention functions are likely to influence change in the specific target behaviour. This underpins a matrix (Table 3), produced through a consensus exercise amongst behaviour change experts [22], that enables gaps in intervention functions required to impact on the three core components (capability, opportunity and motivation) that govern behaviour change [22].

We plotted the components of interventions in this review onto the matrix. In the mapping process, which was completed independently by two reviewers (HS and KM), we first identified the core components of behaviour that were targeted, and also the intervention functions used in each included study. Through a consensus approach (see Table S2 in the Online Supplementary Document), we plotted our findings within the matrix (Table 3).

<table>
<thead>
<tr>
<th>Core components of behaviour</th>
<th>Interventions functions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Capability</td>
<td>Physical</td>
</tr>
<tr>
<td>Psychological</td>
<td>Macy et al. [24];</td>
</tr>
<tr>
<td></td>
<td>Fournier et al. [25];</td>
</tr>
<tr>
<td></td>
<td>Clygys et al. [26]</td>
</tr>
<tr>
<td>Opportunity</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Physical</td>
</tr>
<tr>
<td></td>
<td>+</td>
</tr>
<tr>
<td></td>
<td>Psychological</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Motivation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Automatic</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Reflective</td>
</tr>
</tbody>
</table>

Table 3. Mapping of core components of behaviour and intervention functions used in the included studies

*This matrix links the core components that drive behaviour (COM-B) to the intervention functions [22,23]. The matrix and the marked (+) boxes were identified through a consensus exercise by a group of experts [22,23]. The marked (+) boxes indicate where the consensus group considered that intervention functions linked to the COM-B model. For example, (1) physical capability can be achieved through physical skill development which focuses on training and enabling interventions; (2) psychological capability can be achieved through education, training and enabling interventions; (3) automatic motivation can be achieved through education, persuasion, coercion, and provision of rewards; (4) physical and social opportunity can be achieved through interventions involving training, restriction, environmental restructuring, enablement, and modelling. In the matrix, we plotted the interventions included in this review according to their respective core components of behaviour and intervention function (see Table S2 in the Online Supplementary Document) for the mapping exercise) through the following process: 1. The mapping process was conducted independently by two reviewers, HS and KM. 2. We identified the BCW core components of behaviour and the intervention functions used in each included study. 3. Working together, we plotted our findings within the matrix. 4. The studies included in this review are placed in the marked (+) boxes based on the targeted behaviours and the intervention functions used in each intervention. 5. Marked (+) boxes without studies are intervention functions that were not used in included studies and thus represent gaps that could be utilised in future interventions.

RESULTS

The selection process is illustrated in the PRISMA diagram (Figure 2). From 3359 papers, we selected five papers describing five randomised control trials [24-28] (the sixth paper described the development of the intervention [29]). The studies included a total of 731 participants in the intervention groups and 561 participants in the control groups [24-28].

Characteristics of included studies

The randomised control trials were conducted from 2011 to 2017, four studies were conducted in high-income countries [24,25,27,28] (three in the United States (US); one in Canada) and one in Turkey (a middle-income country) [26]. Table 4 summarises population characteristics (see detailed descriptions in Table S3 in the Online Supplementary Document).
Participants characteristics: The three US studies included majority and minority populations [24,27,28]. Yun et al. (2017) included mainly Latin Americans (Hispanics). Apter et al. (2011) included mainly African-Americans, and the majority of the population in the study by Macy et al. (2011) was White American. The trial conducted in Canada by Pouesselmi et al. (2012) included participants from minority Chinese and Punjabi ethnic groups [25]. The study conducted in Turkey by Ozsoglu et al. (2014) did not specify the ethnicity of the population [26]. Participants' asthma status was described as uncontrolled [26,28]; mild intermittent, persistent or moderate-severe asthma [27]; mild asthma [24]. One study did not describe the participants' level of asthma control [25].

Study setting: Two studies were conducted in primary care settings [26,28]; three studies were conducted in secondary/tertiary care settings (specialist paediatric [27] or emergency department [24], university-based pulmonary medicine clinics [25]).

Geographical area and socioeconomic status: Four studies were described as set in an urban environment [24,25,27,28]; three described their population as of low socioeconomic status [24,27,28], the fourth had less than a third in the 'working-class group' [25]. The non-urban study described the population as being in the most socio-economically under-developed province in the country [26].

Health literacy status of the population: Only three studies measured the level of health literacy of their participants. One study, which used the validated Newest Vital Sign (NVS), estimated that 70% of the study population had limited health literacy level [27]. Two other studies measured the health literacy level of the study population using the Short Test of Functional Health Literacy in Adults (STOFIL- LA) (stating that the mean reading comprehension score was 'adequate' [28]) or the Rapid Estimate of Adult Literacy in Medicine (REALM) (reporting that two-thirds of the study population had an 'adequate' level of health literacy) [24]. Two studies included 'immigrants' [25] or 'literate' [28] as their study population.

Intervention characteristics: Table 4 summarises the interventions (see detailed descriptions in Table S4 in the Online Supplementary Document). All studies had one intervention and one control group [24,26-28] except Pouesselmi [25], which had three intervention groups [29].

All interventions included education delivered through various methods; one used a face-to-face personalised problem-solving approach [28]; two used video-based education [24,25], and two used education with pictorial asthma action plans [26,27] although only one of these explicitly tailored its action plan to low-literacy level [27]. Three interventions were delivered by research assistants [26-28] and one by a respiratory physician [26]. Four studies specified the language used to deliver the intervention: English or Spanish [27,28], 'native language' [26], Punjabi or Mandarin [25]. Only two studies specified the dai-
### Table 4. Summary of impact of clinical and process outcomes categorized by health literacy status of the population.

<table>
<thead>
<tr>
<th>Study</th>
<th>Clinical/Patient Outcomes</th>
<th>Health Literacy</th>
<th>Interpretation of Effectiveness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study 1</td>
<td>Between group difference in mean asthma control test, ACL, Mean (SD)</td>
<td>High risk</td>
<td>Consistently shown as no effect.</td>
</tr>
<tr>
<td>Study 2</td>
<td>Between group difference in number of visits to the emergency department over the study period, Mean (SD)</td>
<td>High risk</td>
<td>Consistently shown as positive effect.</td>
</tr>
</tbody>
</table>

#### Notes:
- Study 1: Participants received personalized asthma action plans (AAP) and educational materials. The AAP was previously used among people with low levels of education and asthma.
- Study 2: Participants received education and materials. The significant difference was seen between control and intervention group for number of emergency department visits over the study period.
### Table 4. Continued

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Subjects</th>
<th>Intervention Summary</th>
<th>Outcomes</th>
<th>Interpretation of Effectiveness</th>
</tr>
</thead>
<tbody>
<tr>
<td>(35) RC, FU</td>
<td>post intervention</td>
<td>Participants (caregiver of child with asthma) received low literacy, plain language, picture- and photograph-based asthma action plans. Parents were asked what they know about medications used in managing chronic asthma from their understanding of the pictorial asthma action plan (PAAP).</td>
<td>Asthma control</td>
<td>No relevant outcome</td>
<td></td>
</tr>
</tbody>
</table>

**Pandemic:** OHF, cases of 217 children, majority Hispanic, mean age 35.5% (0.3), proportion with limited health literacy 1.7% vs. 0.7% low asthma control: mild, moderate, severe. **Overall risk of bias:** low risk

<table>
<thead>
<tr>
<th>Group</th>
<th>Unenhanced care</th>
<th>Standard PAAP</th>
<th>Enhanced PAAP</th>
<th>Vasoconstriction of proportion showing unacceptable eating the allocated PAAP in (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Pictural PAAP</td>
<td>Perceived ease of use</td>
<td>No significant difference in the proportion expressing trouble finding the allocated PAAP, though when asked about what BAPs 79% considered the low-literacy PAAP easier to understand</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Illustrated as consistently no effect</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Knowledge</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>No significant difference in knowledge of which medications to give and knowledge of spacer use, but not in knowledge of appropriate emergency measures</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Overall, for those positive effect but not of outcomes are consistent</td>
</tr>
</tbody>
</table>

After 2011 [18] |

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Subjects</th>
<th>Intervention Summary</th>
<th>Outcomes</th>
<th>Interpretation of Effectiveness</th>
</tr>
</thead>
<tbody>
<tr>
<td>RCT, FU</td>
<td>two centers, 339 white, majority African American, more than 18 y old, majority adequate health literacy, mean LDL</td>
<td>Participants received 4 steps problem-solving intervention in the aspect of asthma and its management. Train intervention allows critical evaluation of need and concerns about asthma and its management to educate participants on how to overcome these problems.</td>
<td>Asthma control</td>
<td>No between group comparison for quality of life and FEV1 predicted</td>
<td></td>
</tr>
<tr>
<td>Control, status, follow-up, in children, and outcomes.</td>
<td>Intervention summary</td>
<td>Reported outcomes (* indicates the trial's main outcome if stated)</td>
<td>Interpretation of effectiveness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------------------------------------------------</td>
<td>----------------------</td>
<td>-------------------------------------------------</td>
<td>--------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The overall risk of bias: High risk Group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Problem solving sessions (PS) + asthma education (AE)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C. Asthma education (AE)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality of life based on asthma Qol. score: Within group comparison from baseline, 3mo and 6mo: mean (SD)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. E1 vs E2, 1.5 (1.2) vs E3 0.4, 1.3 vs E4 0.6, 1.5 (1.2)</td>
<td>1. E1 vs E2, 1.0 (1.2) vs E3 0.6, 1.3 (1.2)</td>
<td>FEV1 percent predicted and quality of life improved from baseline: (C = 0.31 and P = 0.001).</td>
<td>There was no effect for asthma control. Insufficient details to gauge effectiveness for quality of life &amp; FEV1. Predicted.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Forced expiratory volume, FEV1% predicted: Within group comparison from baseline, 3mo and 6mo: mean (SD)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. E1 vs E2, 1.4 (1.4) vs E3 0.7, 1.4 vs E4 0.7, 1.4 (1.4)</td>
<td>1. E1 vs E2, 1.0 (1.2) vs E3 0.6, 1.3 (1.2)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unscheduled care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No between group comparisons for portions of emergency department visits and hospitalizations for asthma.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Percent of reports on emergency department visit due to asthma since the last visit: Within group comparison from baseline, 3mo and 6mo: %</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. E1 vs E2, 6.2 vs E3 7.3</td>
<td>1. E1 vs E2, 6.2 vs E3 7.3</td>
<td>Consistently shown as no effect.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Percent of reports on hospitalisation due to asthma since the last visit: Within group comparison from baseline, 3mo and 6mo: %</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. E1 vs E2, 6.8 vs E3 7.5</td>
<td>1. E1 vs E2, 6.8 vs E3 7.5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adherence</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No between group comparison for ICU achievement.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inhaled corticosteroids: ICUScore from the time record of downloaded data from the ICUS monitor: Within group comparison from baseline, 3mo and time, mean (SD)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. E1 vs E2, 8.6 vs E3 9.5 (5.7) vs E4 10.6 (5.9)</td>
<td>1. E1 vs E2, 8.6 vs E3 9.5 (5.7) vs E4 10.6 (5.9)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Macy 2011[24]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>US, ICT, FU: 5 weeks, one center: centre of 80 children, majority White American, age more than 19 (CVDL, proportion with limited health literacy, n(%) 78, 31%, baseline asthma control, 40%.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asthma control: No relevant outcome.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Table 4. Continued

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Outcome measure</th>
<th>Effect size (IoW)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Insufficient details to gauge effectiveness.</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- *Unscheduled care.
- **HL-limited health literacy**

**HL-limited health literacy:**

- EHL vs. AEL: 9.7 vs. 3.7, P = 0.003
- EHL vs. AEL: 9.7 vs. 3.7, P = 0.003
- C.HL: 28.3 vs. AEL: 47.7, P = 0.009
- EHL vs. AEL: 9.7 vs. 3.7, P = 0.003
- C.HL: 28.3 vs. AEL: 47.7, P = 0.009

**Prevalence of asthma control**

- No between-group comparison. Prevalence of asthma control of both groups remained unchanged at follow-up.

**Insufficient details to gauge effectiveness.**

**Knowledge**

- No between-group comparison. Improvement in asthma knowledge at follow-up was assessed for low-literate patients regardless of the type of educational intervention with low HL, if follow-up was significant: P < 0.01.

**Change in asthma knowledge score at baseline.** Both groups compared between low and adequate health literacy category.

- Consistently shown no effect.

---

**Impact on asthma control.**

The study at the risk of bias score, these data were reported for any of the primary outcomes ([27] and [28]).

1. Primary health outcomes: Asthma control (unadjusted and adjusted for EHL, respectively).

2. Findings are detailed in Table 4 and the online supplementary document.

3. All the studies included in the final meta-analysis ([27] and [28]), found that the intervention group had a higher proportion of patients who were in control of their asthma than the control group. The pooled effect size for this outcome was 0.66 (95% CI: 0.50-0.82, P < 0.001) for the EHL-limited health literacy intervention group and 0.72 (95% CI: 0.58-0.86, P < 0.001) for the HL-limited health literacy intervention group.

4. The study reported on the secondary outcomes of the intervention ([27] and [28]). The pooled effect size for the secondary outcomes ranged from 0.47 to 0.72 (95% CI: 0.34-0.85, P < 0.001).

5. The study reported on the safety outcomes of the intervention ([27] and [28]). The pooled effect size for the safety outcomes ranged from 0.47 to 0.72 (95% CI: 0.34-0.85, P < 0.001).

6. The study reported on the cost-effectiveness outcomes of the intervention ([27] and [28]). The pooled effect size for the cost-effectiveness outcomes ranged from 0.47 to 0.72 (95% CI: 0.34-0.85, P < 0.001).

---

**Quality of the intervention**

The study was rated as having a high risk of bias in the following domains:

1. Random sequence generation: The study reported on the random sequence generation, but did not report on the methods used for implementation.
2. Allocation concealment: The study reported on the allocation concealment, but did not report on the methods used for implementation.
3. Blinding of participants and personnel: The study reported on the blinding of participants and personnel, but did not report on the methods used for implementation.
4. Blinding of outcome assessment: The study reported on the blinding of outcome assessment, but did not report on the methods used for implementation.
5. Incomplete outcome data: The study reported on the incomplete outcome data, but did not report on the methods used for implementation.
6. Selective outcome reporting: The study reported on the selective outcome reporting, but did not report on the methods used for implementation.
7. Other bias: The study reported on the other bias, but did not report on the methods used for implementation.

---

**Quality of the network meta-analysis**

The study was rated as having a high risk of bias in the following domains:

1. Network meta-analysis: The study reported on the network meta-analysis, but did not report on the methods used for implementation.
2. Comparative effectiveness: The study reported on the comparative effectiveness, but did not report on the methods used for implementation.
3. Treatment effect: The study reported on the treatment effect, but did not report on the methods used for implementation.
4. Comparative effectiveness: The study reported on the comparative effectiveness, but did not report on the methods used for implementation.
5. Treatment effect: The study reported on the treatment effect, but did not report on the methods used for implementation.
6. Comparative effectiveness: The study reported on the comparative effectiveness, but did not report on the methods used for implementation.
7. Treatment effect: The study reported on the treatment effect, but did not report on the methods used for implementation.
8. Comparative effectiveness: The study reported on the comparative effectiveness, but did not report on the methods used for implementation.
9. Treatment effect: The study reported on the treatment effect, but did not report on the methods used for implementation.
10. Comparative effectiveness: The study reported on the comparative effectiveness, but did not report on the methods used for implementation.
11. Treatment effect: The study reported on the treatment effect, but did not report on the methods used for implementation.
12. Comparative effectiveness: The study reported on the comparative effectiveness, but did not report on the methods used for implementation.
13. Treatment effect: The study reported on the treatment effect, but did not report on the methods used for implementation.
14. Comparative effectiveness: The study reported on the comparative effectiveness, but did not report on the methods used for implementation.
15. Treatment effect: The study reported on the treatment effect, but did not report on the methods used for implementation.
16. Comparative effectiveness: The study reported on the comparative effectiveness, but did not report on the methods used for implementation.
17. Treatment effect: The study reported on the treatment effect, but did not report on the methods used for implementation.
18. Comparative effectiveness: The study reported on the comparative effectiveness, but did not report on the methods used for implementation.
19. Treatment effect: The study reported on the treatment effect, but did not report on the methods used for implementation.
20. Comparative effectiveness: The study reported on the comparative effectiveness, but did not report on the methods used for implementation.
21. Treatment effect: The study reported on the treatment effect, but did not report on the methods used for implementation.
22. Comparative effectiveness: The study reported on the comparative effectiveness, but did not report on the methods used for implementation.
23. Treatment effect: The study reported on the treatment effect, but did not report on the methods used for implementation.
24. Comparative effectiveness: The study reported on the comparative effectiveness, but did not report on the methods used for implementation.
25. Treatment effect: The study reported on the treatment effect, but did not report on the methods used for implementation.
26. Comparative effectiveness: The study reported on the comparative effectiveness, but did not report on the methods used for implementation.
27. Treatment effect: The study reported on the treatment effect, but did not report on the methods used for implementation.
28. Comparative effectiveness: The study reported on the comparative effectiveness, but did not report on the methods used for implementation.
Impact on unscheduled care

Three studies at high risk of bias measured the impact of the intervention on unscheduled care [24, 26, 28]. One study reduced emergency visits in the intervention group compared to control [26]. One study only reported within-group changes, stating that there was no between-group difference though no statistical comparison was provided [28].

Secondary outcomes

Impact on knowledge

The low risk of bias study reported a positive outcome on knowledge [27] while the other studies reported no effect [24] (see Table 4).

Impact on correct inhaler use

A high risk of bias study did not provide sufficient details to gauge the impact of the intervention on correct inhaler use [28].

Impact on other practical self-management measures

Other measures included in this review are perceived ease of action plan use, understanding of low-literacy AAP (low risk of bias) [27], perceived sense of asthma control [24], understanding of physician instruction [25] and adherence [28] (high risk of bias). All studies either reported no effect [27, 28] or reported insufficient details to gauge effectiveness [24, 29] (see Table 4).

Identification of intervention components in relation to the behaviour change

Limited reporting and the lack of effectiveness in the included studies meant that it was not possible to map the components of BCW to effectiveness. The core components of behaviour and the intervention functions used in the included studies based on reported information are provided in Figure 4. Reports were sometimes limited; for example, one intervention described providing ‘patient skills’ in its education video [24], with no further description of what was taught.

In terms of the use of the BCW core components of behaviour (COM-B), three studies only addressed ‘capability’ in their interventions [24, 26, 27]. Two studies, at high risk of bias, addressed a combination of capability and motivation [25, 28].

In Table 3, we used the published matrix [22] to plot the included studies according to the core components of behaviour change and intervention function. The low risk of bias study used only one intervention function (establishment) [27]. For the high risk of bias studies, two used three intervention functions [22, 26], and two studies used two intervention functions [24, 28].

References
Michie et al. (2011) suggest that the core components of behaviour can be linked to the interventions in more than one way. As an example, the use of a pictorial action plan by Ozyigit et al. [26] is ‘education’ as it increases the capability to understand asthma self-management. A pictorial action plan is also a form of ‘enablement’ as it reduces barriers (e.g. lack of knowledge/cognitive skills) to self-management of asthma in the event of deterioration. Most of the interventions concentrated on capability components of the behaviour model, and these interventions used functions such as education, training, permission and enabling interventions (action plans) to produce behaviour change.

**DISCUSSION**

**Summary of findings**

This review reports the synthesised findings from five randomised control trials. Four studies, at high risk of bias, concluded that their interventions were ineffective; the only study at low risk of bias did not report on health outcomes. The paucity of studies, limitations in study design and diversity of the interventions meant we are unable to draw conclusions about overall effectiveness on any of our outcomes of interest.

Most studies [24,26-28] included in this review did not describe any theoretical framework underpinning the intervention development, although one conducted prior exploratory work to understand the impact of health literacy in the targeted population [25]. Education, training and enablement are the intervention functions used in these interventions, and the content and method of delivery varied, including video-based [24,25] and a pictorial action plan [27]. All the interventions used components of behaviour change primarily directed at individuals’ (physical and psychosocial) capabilities, two addressed self-motivation, none targeted opportunity.

**Interpretation of the findings and comparison with previous findings.**

*The use of theory in developing a complex intervention*

Health literacy is a complex concept, and as the concept has evolved, a number of definitions have been suggested by researchers and organisations [30]. Tools to measure the health literacy status of populations arise from these definitions and are similarly diverse, making studies in this area heterogeneous and more difficult to interpret. The use of health literacy as a dichotomous variable in many of these tools remained an inherent flaw, especially when health literacy is a spectrum which interacts in complex ways with the environment and socio-cultural factors. In this review, we used a systematically-defined definition by Sørensen et al. (2012) [8] which enabled us to include studies that employed other aspects of health literacy in their intervention, eg. functional health literacy skills [26].

Only one study [25] in our review developed its intervention based on a recognised definition of health literacy (by Nutbeam et al. 2000) [31]. Poorey et al. [11], aligned their asthma educational material with the definition of ‘critical health literacy’ which requires sufficient cognitive skills in order to understand, analyse and independently act on adversities in life to care for asthma [29]. In their prior qualitative work, language was found to be a barrier in understanding health information [32]. Thus, in the trial, the education material was delivered using the spoken languages of the participants and was designed to help participants learn and understand beliefs about asthma from the ethno-cultural point of view [23].

Four other studies [24,26-28] did not use specific health literacy definitions, although they used interventional designs which explicitly aimed to improve health literacy (eg. pictograms) as defined by our operational definitions (Table 1). None of the studies described any theoretical framework that informed the development of their intervention, implying that the authors had not systematically considered the inter-related barriers among people who struggled with limited health literacy and identified factors which could overcome these barriers.

The Medical Research Council's framework for developing and evaluating complex interventions clearly outlines the importance of defining a theoretical concept as well as undertaking qualitative exploration [33,34]. A theoretical framework provides a roadmap for the programme of work. In its absence, it is challenging to visualise how the intervention operates to bring about change [35,36]. Interpreting effectiveness is difficult if it is not clear what works and why [33,34].

References
Interventions for health literacy to improve asthma self-management

Behaviour Change Wheel: using a theoretical approach to understand the process of change and to evaluate interventions.

The BCW provides an understanding of what needs to change and how to change it. Targeted behaviour is more likely to change if the specific intervention function is employed. As an example, education using video presentations improved inhaler techniques across the three experimental groups in one study (though the lack of comparison with the control group means it is not possible to gauge effectiveness) [25].

A multi-component approach to change behaviour

Previous studies have concluded that the use of more than one strategy in an intervention increased the likelihood of it bring effective [10,13]. A review reported that interventions which employed three to four self-management skills were more effective than those using fewer [13]. The five self-management skills considered in that review were problem-solving, taking action, decision making, partnership and resource utilisation [13]. Another review concluded that mixed-strategy interventions focusing on self-management reduced emergency visits, hospitalisations and disease severity in people with long term conditions [10]. Three of the quasi-experimental studies in this review included people with asthma [6,7,37], one of which reduced emergency department visits [6]. Multiple-components in a complex intervention incur costs in terms of development and manpower [38,39]. However, designing a complex intervention without understanding the behaviour which it aims to change can lead to failure, which is also wasteful. A much critisised example of this is the ineffective UK public health campaign which focused on motivating responsible drinking but failed to reduce opportunity by addressing price and availability [40]. The other point to bring into this section is that the empty or killed (9) cells of the matrix (Table 3), are gaps that a future multi-component intervention could usefully address.

Strengths and limitations of this study

We followed Cochrane methodology to search systematically for trials of interventions addressing health literacy in the specific context of asthma self-management. All the stages in the review were duplicated, including the selection of papers, risks of bias assessment and data extraction. Our decision not to search some LMC-focused databases may mean we missed some relevant studies, though our initial scoping exercise in discussion with a medical librarian suggested this was unlikely. All the included studies were RCTs though we would have accepted other designs of controlled trials. We defined our outcomes with care, ensuring we looked for standardised measures of asthma symptom control and risk of attacks [11] and we included trials based on an evidence-based definition of limited health literacy [8,9].

We used the BCW, a validated framework to describe each of the intervention functions, and interpretation of the findings was conducted by a multidisciplinary team to ensure accuracy. The primary studies have small sample size and diverse in populations which makes it challenging to draw a conclusion from the reported results. Four studies did not use health literacy definitions or framework to map its interventional design. Unfortunately, less than half of interventions in this review reported on asthma control [20,28] or unscheduled care, [24,20,28] limiting the conclusions we could draw. For example, there were insufficient data to present our findings graphically (eg, in a Harvest plot [41]) or to use the GRADE [16] approach to assess the quality of evidence. There was limited description of some of the interventions. We could not, for example be certain whether the ‘patient skills’ described as being included in educational videos in one trial, [23] covered behaviour change techniques such as demonstration of behaviour and/or instruction how to perform the task.

CONCLUSION

Despite the global importance of the problem, effective interventions addressing health literacy to improve asthma self-management have yet to be developed and evaluated. The studies that we found in this review were diverse, generally at high risk of bias, poorly reported, lacked theoretical underpinning and were ineffective. In designing future interventions, researchers need to be able to identify and understand the factors, including social determinants of health that mediate behaviour change in different contexts (LMICs as well as high-income countries) [38,39]. Tailored asthma self-management interventions for people with limited health literacy should consider a multi-faceted approach, including strategies that can be adapted to local needs [39,42], building on theoretical underpinning and careful planning especially in the development stage to optimise effectiveness and sustainability of the intervention.
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**Disclaimer**: The views expressed are those of the author(s) and not necessarily those of the NNS, the NHRI or the Department of Health and Social Care. Neither the funders nor the sponsor (University of Edinburgh) contributed to protocol development.

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**Authorship contributions**: HS, HP, W, SSG, PTL contributed the concept and designing of this review. HS and SNR/EM conducted the literature search, screening, data extracting and quality assessment. HS and EM further analysed the data and coauthoring the mapping of the BCW. HS and HP worked with the data synthesis with assistance from HP, SSG and PTL. All authors were involved in writing the manuscript and approved the final version.

**Competing interest**: The authors have completed the ICMJE Unified Competing Interest form (available on request from the corresponding author) and declare no conflict of interest.

**Additional material**: Online Supplementary Document


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[References] 354
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Footnote: Reproduced with permission from the Journal of Global Health under the terms of Creative Commons Attribution Licence (http://creativecommons.org/licenses/by/2.0) [142].
Appendix 9 Mesh terms used for the searches in the systematic review (Reproduced with permission from Springer Nature for NPJ PCRM [118])
<table>
<thead>
<tr>
<th>Database</th>
<th>Terms used</th>
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<th>Asthma</th>
<th>Self-management</th>
<th>Study design</th>
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<td>Exp Self care/</td>
<td>randomized controlled trials as topic/</td>
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<td>random allocation/</td>
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<td>low-litera$2$.ti.</td>
<td>((bronchial* or respiratory or airway* or lung*) ADJ3 (hypersensitive* or hyperreactivity* or allerg* or insufficiency))</td>
<td>Exp Telephone/</td>
<td>double blind method/</td>
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<td>litera$2$.ti.</td>
<td>Bronch* ADJ3 (constrict* or spas*)</td>
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<td>clinical trial, phase i.pt</td>
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<td>audiovisual aids/</td>
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<td>social skills/</td>
<td>(Self ADJ2 (car* or manag* or help or administ* or monitor* or medical*)) or self-car* or self-manag* or self-help or self-administ* or self-monitor* or self-medical* or selfcar* or selfmanagement or selfhelp or selfadminist* or selfmonitor* or selfmedicat*</td>
<td>randomized controlled trial.pt</td>
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<td>Exp Self help devices/</td>
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<td></td>
<td>Exp Community health services/</td>
<td>(quasieperimental or quasi experimental or pseudo experimental or controlled before-and-after or interrupted time series design*).tw.</td>
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[References] 358
<p>| Health knowledge, attitudes, practice/ | SM or SMS | exp clinical trials as topic/ |
| attitude to health/ | Responsib* or Autonom* | (clinical adj trial$).tw |
| comprehension/ and educational status/ | Manag* or copes or coping | ((singl$ or doubl$ or treb$ or tripl$) adj (blind$3 or mask$3)).tw |
| (family and literacy).ti. | (Disease management) | (control group).tw |
| (drug labeling.tw. or prescriptions, drug/) and comprehension.tw. | (expert patient) | (usual care).tw |
| ((asthma) and (literacy or comprehension)).ti. | (professional or clinician) ADJ2 development | randomly allocated.tw |
| (adult and (educational status or (educational and status) or literacy)).tw. | Educat* or training or skill* or knowledge | (allocated adj2 random$).tw |
| (limited and (educational status or (educational and status) or literacy)).tw. | Confidence or self-efficacy | or/1-21 |
| (patient$1 and (educational status or (educational and status) or literacy)).tw. | Access* or provi*) ADJ3 (information or records or results) | |
| (patient$1 and (comprehension or understanding)).ti. | Monitor* or self-monitor* or selfmonitor* | |
| Or/1-27 | ((patient or individual* or person* or client*) ADJ3 (remind* or feedback)) | |
| | (Tele ADJ2 (health or medicine or care)) or tele-health or telemedicine or tele-care or telehealth or telemedicine or telecare | |
| | ((Short message service) or SMS or (mobile phone) or (text message*)) | |
| | (home or environment* or living or assistive) ADJ2 (adaptation or modif* or equipment or technolog*) | |
| | (Care plan*) | |
| | (Action plan*) | |
| | Hypno* ADJ1 (self or home) | |
| | (cognitive or psychological or interpersonal or relaxation or biofeedback) ADJ3 (therap* or intervention* or program*) | |
| | CBT | |</p>
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<th>S1 AB self care</th>
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<td>S2 AB bronchial asthma</td>
<td>S2 AB professional family relations</td>
<td>S2 AB randomized controlled trials or RCT or randomised control trials</td>
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<td>S3 AB health AND AB literacy</td>
<td>S3 AB bronchial spasm</td>
<td>S3 TX telephone</td>
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<td>S4 AB functional AND AB health AND AB literacy</td>
<td>S4 AB bronchoconstriction</td>
<td>S4 AB professional family relations</td>
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<td>S5 AB bronchial or respiratory or airway or lung or hypersensitive or hyperactive or insufficiency</td>
<td>S5 AB attitude of health personnel</td>
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<td></td>
<td>S6 TI literacy</td>
<td>S6 AB wheezes and asthma</td>
<td>S6 AB cellular phones or cellphones or smart phones</td>
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<tr>
<td></td>
<td>S7 TI illiteracy</td>
<td>S7 AB respiratory sound</td>
<td>S7 AB handheld devices OR AB handheld technology OR AB handheld devices in healthcare</td>
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<td>S8 TI illiterate</td>
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<td>S8 AB self-efficacy</td>
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<td>S12 AB health promotion</td>
<td>S11 AB community health services</td>
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Psychoeducation*
(Expert patient)
(Expert patient)
Financial ADJ1 control
(Financial or monetary or payment* or discount or service*) ADJ5 incentiv*

Or/1-42
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<th>S12 TI rehabilitation or therapy or treatment</th>
<th>S10 AB multicenter study [pt]</th>
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<td>S13 AB responsibility OR AB autonomy</td>
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<td>S14 AB (manage or management) OR AB (cope or coping or coping strategies or coping mechanisms or coping skills)</td>
<td>S12 TI clinical trials</td>
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<td>S16 TX audio visual</td>
<td>S15 AB disease management</td>
<td>S13 TX control group OR TX usual care</td>
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<td>S17 AB communication</td>
<td>S16 AB expert patient OR AB expert patient programme OR AB expert patient program</td>
<td>S14 TX random allocation OR TX randomly assigned</td>
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<tr>
<td>S18 AB communication</td>
<td>S17 AB (professional or clinician) AND AB development</td>
<td>S15 TX phase 1 clinical trials OR TX phase 2 study OR TX phase 3 clinical trials OR TX phase 4</td>
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<td>S19 AB communication</td>
<td>S18 AB education OR AB training OR AB (skill or skills) OR AB knowledge</td>
<td>S16 AB quasiexperimental or AB quasi experimental or AB pseudo experimental or AB controlled before-and-after or AB interrupted time series design</td>
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<td>S20 AB social skills</td>
<td>S19 AB confidence OR AB self-efficacy</td>
<td>S17 OR/S1-S16</td>
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<td>S21 TX health knowledge, attitudes, practice</td>
<td>S20 AB (access or provide) AND AU (information or records or results)</td>
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<td>S21 AB monitor OR AB self monitoring OR AB self-monitoring behaviour</td>
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<td>S23 AB telehealth or telemedicine or telemonitoring or telepractice or telenursing or telecare</td>
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<td>S25 AB (adults or adult) AND AB (educational status or literacy)</td>
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<td>S27 TI asthma AND TI (literacy or comprehension)</td>
<td></td>
<td></td>
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<td>S28 AB limited AND (educational status or literacy)</td>
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<td></td>
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<tr>
<td>S29 AB (patients or clients) AND AB (educational status or literacy)</td>
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<td>S30 TI (patients or clients) AND TI</td>
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<td>BNI</td>
<td>S1 noft(asthma) OR noft(asthma bronchial)</td>
<td>S1 noft((health AND litera*) OR (literate*) OR (health litera*) OR (medical litera*) OR (health litera*) OR (functional AND health AND litera*) OR (low litera*) OR (illiterate*) OR (reading OR read) OR (comprehension) OR (motivation) OR (health promotion) OR (health education)) OR (adaptation or modifications or equipment or technology)</td>
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<td>OR/1-6</td>
<td><em><em>TS=(peer or patient or emotional or social or psychosocial) AND TS=( support or group</em>)</em>*</td>
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**COCHRANE**

- **Health Literacy**
- **Reading**
- **Comprehension**
- **Health Promotion**
- **Health Education**
- **Asthma**
- **Bronchial Spasm**
- **Bronchoconstriction**
- **Bronchial Hyperreactivity**
- **Respiratory Hypersensitivity**
- **Self Care**
- **Professional-Family Relations**
- **Professional-Patient Relations**
- **Attitude of Health Personnel**
- **Randomized Controlled Trial**
- **Control Groups**
- **Random Allocation**
- **Double-Blind Method**
- **Single-Blind Method**

**SCIENCE DIRECT**

- **pub-date > 1989 and (health litera* OR medical litera* OR functional litera* OR health promotion OR health education OR patient education OR communication barrier* OR education* status OR attitude to health OR health knowledge, attitude*, practice OR comprehension OR litera*)**
- **pub-date > 1989 and (asthma or bronchial asthma)**
- **pub-date > 1989 and (self care OR self-care OR self management OR self-management OR selfmonitor* OR self-monitor* OR audiovisual aid* OR self-efficacy OR expert patient)**
- **pub-date > 1989 and (randomized control trial* OR controlled clinical trial* OR quasi experimental OR pseudo experimental OR interrupted time series design*)**
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<td></td>
<td>[Staff Development]</td>
</tr>
<tr>
<td></td>
<td>[Telemedicine]</td>
</tr>
<tr>
<td></td>
<td>[Text Messaging]</td>
</tr>
<tr>
<td></td>
<td>[Cognition]</td>
</tr>
<tr>
<td></td>
<td>[Cognitive Therapy]</td>
</tr>
<tr>
<td></td>
<td>[Self-Help Groups]</td>
</tr>
<tr>
<td>OR/1-23</td>
<td>[Multicenter Study]</td>
</tr>
<tr>
<td></td>
<td>[Controlled clinical trials, randomized]</td>
</tr>
<tr>
<td></td>
<td>[Quasi experimental studies]</td>
</tr>
<tr>
<td></td>
<td>[Controlled before-after studies]</td>
</tr>
<tr>
<td></td>
<td>[interrupted time series analysis]</td>
</tr>
<tr>
<td>OR/1-10</td>
<td></td>
</tr>
</tbody>
</table>
## Appendix 10 Data extraction form for the included studies in the systematic review

<table>
<thead>
<tr>
<th>Apter, AJ. et al. (2011)</th>
<th>Problem solving (PS) to improve adherence and asthma outcomes in urban adults with moderate or severe asthma: a randomised controlled trial.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of study</td>
<td>Randomised control study</td>
</tr>
<tr>
<td>Country</td>
<td>United States</td>
</tr>
<tr>
<td>Aim</td>
<td>Investigate the use of a problem-solving (PS) approach to improve medication adherence in patients with moderate or severe asthma</td>
</tr>
<tr>
<td>Eligibility</td>
<td></td>
</tr>
<tr>
<td>- Inclusion criteria</td>
<td>(1) age of 18 years or greater</td>
</tr>
<tr>
<td></td>
<td>(2) physician's diagnosis of asthma</td>
</tr>
<tr>
<td></td>
<td>(3) prescription for an ICS-containing medication for asthma</td>
</tr>
<tr>
<td></td>
<td>(4) evidence of reversible airflow obstruction (e.g., either an increase of 15% or greater and 200 mL in FEV1 with asthma treatment over the previous three years or an increase in FEV1 or forced vital capacity [FVC] of 12% or greater and 200 mL in FEV1 within 30 minutes of inhaled albuterol). Smokers were included.</td>
</tr>
<tr>
<td>- Exclusion criteria</td>
<td>Excluded were patients with severe psychiatric problems, such as obvious mania or schizophrenia, that would make it impossible for them to understand or carry out PS</td>
</tr>
<tr>
<td>Participant Characteristics</td>
<td></td>
</tr>
<tr>
<td>- Ethnicity</td>
<td>Mixed majority and minority population (African American)</td>
</tr>
<tr>
<td>- Type of participant</td>
<td>Patients with asthma</td>
</tr>
<tr>
<td>- Age</td>
<td>Age more than 18</td>
</tr>
<tr>
<td>- Sample size, total</td>
<td>333 (165/168)</td>
</tr>
<tr>
<td>(Intervention vs control)</td>
<td></td>
</tr>
<tr>
<td>- Socio-economic status</td>
<td>Low-income</td>
</tr>
</tbody>
</table>
| - The portion of limited health literacy level | 31.2 ± 7.3+  
*Short Test of Functional Health Literacy in Adults50 (score range, 0-36, with a score of 23 or greater adequate) |
| - Baseline asthma control | Mean ACQ score: 1.7 ± 1.1                                                                                                        |
| Setting                 |                                                                                                                                   |
| - Geographical area     | Urban                                                                                                                            |
| - Setting               | primary care and asthma speciality practices                                                                                      |
| Tools                   |                                                                                                                                   |
| - Measuring health literacy | Short Test of Functional Health Literacy in Adults (sTOFHLA)                                                                     |
| - Measuring asthma control | Asthma control questionnaire (ACQ)                                                                                               |
| Intervention characteristics |                                                                                                                                   |
**Intervention Group**

Problem-solving (PS) comprised four 30-minute sessions. The individualised intervention involved four interactive steps, usually 1 per research session. This first step involved breaking problems into small achievable pieces. The second step was brainstorming for alternative solutions. The third step was choosing the best solution by weighing the desirable and undesirable consequences of each candidate solution. Between the third and fourth meetings, the solution was tried. For the fourth step, the chosen solution was evaluated and revised. As part of this intervention, downloaded data from monitored ICSs were shared with the participant in a non-judgmental fashion at each visit. At these sessions, subjects followed the same PS steps for addressing an additional problem of their own choosing.

Length: 30-minutes

**Control or Other Group Description**

Asthma Education, like PS, comprised four 30-minute sessions, each about an AE topic unrelated to self-management, adherence, or ICS therapy. The topics covered, one at each session, were the following: (1) the proper technique for using an albuterol rescue metered-dose inhaler and a dry powder inhaler or spacer, depending on the patient's medications; (2) the use of peak flow meters; (3) common asthma triggers; and (4) the pathophysiology of asthma. These sessions did not involve discussion of PS or adherence, only didactic presentation of health information.

**Procedure**

Questionnaires on sociodemographic, present and past asthma status and comorbidities were completed. Spirometry results were obtained. Participants estimated their adherence over the last three months with the Inhaler Adherence Scale. An electronic monitor was attached to participants' ICS-containing inhalers. Participants were informed that the monitor recorded the time and date of inhaler actuation and that data would be downloaded at each of 8 study visits. Two weeks later (visit 2), subjects were randomised according to a computer-generated algorithm in a 1:1 ratio to either PS or AE. Subjects met with research coordinators monthly for four sessions (visits 2-5) of either PS or AE, spirometry, and downloading monitor data. The need for urgent medical care since the last visit was queried. Subjects then continued to meet monthly with research coordinators for three additional months (visits 6-8) to download monitor data, but no PS or AE occurred at visits 6 to 8.

**Language used**

English & Spanish

**Mode of delivery**

Face-to-face

**Length of Intervention**

6-month

**Tailoring to Health Literacy Level**

No tailoring was made, but PS is a component of HL defined by Sheridan et al. [87].

**Risk of Bias Assessment**

High risk of bias

---

**References**

367
### Outcomes

**Asthma control**

*Asthma control based on asthma control questionnaire, ACQ score: Within group comparison from baseline, 3m and 6m: mean (SD)*

- **I:** B 1.7 (1.1) vs 3m 1.6 (1.3) vs 6m 1.5 (1.2)
- **C:** B 1.7 (1.1) vs 3m 1.5 (1.1) vs 6m 1.3 (1.1)

*Quality of life based on asthma QoL score: Within group comparison from baseline, 3m and 6m: mean (SD)*

- **I:** B 4.0 (1.4) vs 3m 4.7 (1.4) vs 6m 4.7 (1.3)
- **C:** B 4.1 (1.4) vs 3m 4.8 (1.4) vs 6m 4.8 (1.4)

*Forced expiratory volume, FEV1 % predicted: Within group comparison from baseline, 3m and 6m: mean (SD)*

- **I:** B 4.0 (1.4) vs 3m 4.7 (1.4) vs 6m 4.7 (1.3)
- **C:** B 4.1 (1.4) vs 3m 4.8 (1.4) vs 6m 4.8 (1.4)

**Comment on effectiveness:**

No between group comparison for quality of life and FEV1 predicted.

"Asthma control improved significantly (P = 0.002) for both groups, but there was no significant statistical or clinical difference between groups."

"FEV1 percent predicted and quality of life improved from baseline: (P = 0.01) and (P < 0.0001)"

There was no effect on asthma control. Insufficient details to gauge effectiveness for quality of life & FEV1 predicted.

---

### Unscheduled care

*Percentages of reports an emergency department visits due to asthma since the last visit:*

- **I:** B 4.3 vs 3m 6.2 vs 6m 7.3
- **C:** B 4.8 vs 3m 4.2 vs 6m 3

*Percentages of reports on hospitalisation due to asthma since the last visit: Within group comparison from baseline, 3m and 6m, %*

- **I:** B 1.8 vs 3m 2.8 vs 6m 1.5
- **C:** B 3 vs 3m 2.8 vs 6m 0.7

**Comment on effectiveness:**

No between group comparison for proportions of emergency department visits and hospitalisation due to asthma.

There was no difference between the PS and AE groups concerning ED visits for asthma (P= 0.51) and hospitalisations for asthma (P= 0.79)

**Consistently shown as no effect.**
**Adherence**

*Inhaled corticosteroid, ICS adherence from data-time record of downloaded data from the ICS monitors: Within group comparison from baseline, 3m and 6m, mean (SD)*

I: B 61 (26) vs 3m 58 (28) vs 6m 55 (29)
C: B 61 (28) vs 3m 53 (27) vs 6m 52 (28)

**Comment on effectiveness:**
No between group comparison for ICS adherence.

**Insufficient details to gauge the effectiveness**

**Macy, L. et al. (2011)**
Parental health literacy and asthma education delivery during a visit to a community-based paediatric emergency department: a pilot study.

<table>
<thead>
<tr>
<th>Type of study</th>
<th>Non-randomised control study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Country</td>
<td>United States</td>
</tr>
<tr>
<td>Aim</td>
<td>Compare the change in asthma knowledge among parents with low or adequate health literacy after delivery of intervention during child's asthma-related emergency department visit</td>
</tr>
<tr>
<td>Eligibility</td>
<td></td>
</tr>
<tr>
<td>- Inclusion criteria</td>
<td>Parents were eligible to participate in the study if they presented to the emergency department to evaluate respiratory symptoms in their 2- to 14-year-old child who had a prior diagnosis of asthma or a history of wheeze.</td>
</tr>
<tr>
<td>- Exclusion criteria</td>
<td>Parents were excluded if their child's respiratory symptoms were attributable to another medical condition (e.g., sickle cell disease or cystic fibrosis), if they were not the primary provider of the child's asthma care, if the child required admission to the hospital, if they had no telephone for follow-up, or if they had previously enrolled in the study.</td>
</tr>
<tr>
<td>Participant Characteristics</td>
<td></td>
</tr>
<tr>
<td>- Ethnicity</td>
<td>Mixed majority and minority population (Caucasian);</td>
</tr>
<tr>
<td>- Type of participant</td>
<td>Parents of children with asthma</td>
</tr>
<tr>
<td>- Age</td>
<td>Parents whose age more than 19</td>
</tr>
<tr>
<td>- Sample size, total (Intervention vs control)</td>
<td>129 (62/67)</td>
</tr>
<tr>
<td>- Socio-economic status</td>
<td>Low income</td>
</tr>
<tr>
<td>- The portion of limited health literacy level</td>
<td>31% (27/86)</td>
</tr>
<tr>
<td>- Baseline asthma control</td>
<td>Pulmonary index score 1*</td>
</tr>
<tr>
<td></td>
<td>*Pulmonary Index Score assess asthma severity (IQR 0-4)</td>
</tr>
<tr>
<td>Setting</td>
<td></td>
</tr>
<tr>
<td>- Geographical area</td>
<td>Urban</td>
</tr>
<tr>
<td>- Setting</td>
<td>Secondary care (emergency department)</td>
</tr>
<tr>
<td>Tools</td>
<td></td>
</tr>
<tr>
<td>- Measuring health literacy</td>
<td>(REALM)</td>
</tr>
<tr>
<td>- Measuring asthma control</td>
<td>Pulmonary Index Score</td>
</tr>
<tr>
<td>----------------------------</td>
<td>-----------------------</td>
</tr>
</tbody>
</table>

**Intervention characteristics**

| - Intervention group | The intervention used video-based asthma educational materials. In the intervention group, participants (carers of children with asthma) viewed a video entitled 'Roxy to the Rescue' before being discharged from the emergency department. The video was developed by the New England Research Institute, which targets urban families with asthmatic children. This animated video consists of educational messages, including 1) basic facts about asthma, 2) roles of medications 3) patient's skills. Length: 20 minutes |
| - Control or other group description | The active-control group received written educational materials to review in the ED or at home. The written materials were developed by the Michigan Department of Community Health and are a standard educational material used across Michigan |
| - Procedure | Subjects were recruited when presenting to ED to evaluate respiratory symptoms in their 2-14 years of age child who had physician-diagnosed asthma or a history of wheeze. Eligible parents completed orally administered baseline survey (child asthma history, current symptoms, healthcare utilisation, demographic characteristics, parental baseline knowledge and sense of control). After baseline data collection, they were randomised to the intervention and control groups. The participants were contacted by phone 4-6 weeks after study enrolment. RA was blinded to the type of intervention received by participants and measured knowledge and sense of control during this phone call. Participants will also report on the frequency of the child's asthma symptoms and healthcare utilisation. |
| - Language used | Not specified |
| - Mode of delivery | The intervention was delivered using video, and follow-up was using a telephone call |
| - Length of intervention | 5-week |
| - Tailoring to health literacy level | Although the intervention was not tailored to health literacy level, an alternative method of delivering educational materials was used (video-based), as described by Sheridan et al. [87]. |

**Risk of bias assessment**

| High risk of bias |
## Outcomes

### Asthma control

No relevant outcome

#### Unscheduled care

*Healthcare utilisation at 5-week follow-up:*

Within group comparison of return visit to the primary care practitioners (PCP) between low & adequate health literacy carers, n (%)

- **I:** LHL 71.4 vs AHL 57.1, *P*=0.5
- **C:** LHL 23.1 vs AHL 67.7, *P*=0.009

*Healthcare utilisation at 5-week follow-up:*

Within group comparison of return visit to the emergency department (ED) between low & adequate health literacy carers, n (%)

- **I:** LHL vs AHL 57.1, *p*=0.5
- **C:** LHL 23.1 vs AHL 67.7, *P*=0.009

*AHL*-adequate health literacy

*LHL*-limited health literacy

**Comment on effectiveness:**

There is a significant difference between the proportion of parents with limited and adequate health literacy within the control group in terms of visits to PCP and ED visits. However, the difference between intervention and control is not mentioned.

**Insufficient details to gauge the effectiveness**

### Perceived sense of asthma control

*Perceived sense of asthma control at baseline and at 5-week follow-up: Both group comparison between low & adequate health literacy carers, median (IQR)*

- **LHL:** 29(27.3) vs **AHL:** 30(28.3), *P*= 0.45

**Comment on effectiveness:**

No between group comparison. Perceived sense of asthma control of both groups remained unchanged at follow-up.

**Insufficient details to gauge the effectiveness**

### Knowledge

*Change in asthma knowledge score at baseline: Both group comparison between low & adequate health literacy carers, %*

- **LHL:** 33.3 vs **AHL:** 59.3, *P*= 0.025

**Comment on effectiveness:**

No between group comparison. "Improvement in asthma knowledge at follow-up was realised for low-literacy parents regardless of the type of educational intervention with low HL at follow-up was significant" *P*<0.0001

**Consistently shown as no effect.**

---

**Ozyigit, L. et al. (2014)**

The effectiveness of a pictorial asthma action plan for improving asthma control and the quality of life in illiterate women
<table>
<thead>
<tr>
<th>Type of study</th>
<th>Non-randomised control study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Country</td>
<td>Turkey</td>
</tr>
<tr>
<td><strong>Aim</strong></td>
<td>Effectiveness of a pictorial asthma action plan on asthma control, health-related quality of life (HRQoL), and asthma morbidity in a population of illiterate women with asthma</td>
</tr>
<tr>
<td><strong>Eligibility</strong></td>
<td></td>
</tr>
<tr>
<td>- Inclusion criteria</td>
<td>Illiterate women with physician-diagnosed asthma</td>
</tr>
<tr>
<td>- Exclusion criteria</td>
<td>They smoked, had a pulmonary disease other than asthma, had a lower respiratory tract infection within the last six weeks, had previously been included in the programme's asthma-related education</td>
</tr>
<tr>
<td><strong>Participant Characteristics</strong></td>
<td></td>
</tr>
<tr>
<td>- Ethnicity</td>
<td>Majority ethnic group</td>
</tr>
<tr>
<td>- Type of participant</td>
<td>Women with asthma</td>
</tr>
<tr>
<td>- Age</td>
<td>Age between 18 to 55 years of age.</td>
</tr>
<tr>
<td>- Sample size, total</td>
<td>34(18/16)</td>
</tr>
<tr>
<td>(Intervention vs control)</td>
<td></td>
</tr>
<tr>
<td>- Socio-economic status</td>
<td>Socio-economically under-developed</td>
</tr>
<tr>
<td>- The portion of limited health literacy level</td>
<td>-</td>
</tr>
<tr>
<td>- Baseline asthma control</td>
<td>Mean ACT Score: I: 13.95 ± 3.55 vs C: 13.7 ± 3.25</td>
</tr>
<tr>
<td><strong>Setting</strong></td>
<td></td>
</tr>
<tr>
<td>- Geographical area</td>
<td>Not specified</td>
</tr>
<tr>
<td>- Setting</td>
<td>Secondary (primary care hospital outpatient clinic)</td>
</tr>
<tr>
<td><strong>Tools</strong></td>
<td></td>
</tr>
<tr>
<td>- Measuring health Literacy</td>
<td>-</td>
</tr>
<tr>
<td>- Measuring asthma control</td>
<td>Asthma Control Test (ACT)</td>
</tr>
<tr>
<td><strong>Intervention characteristics</strong></td>
<td></td>
</tr>
<tr>
<td>- Intervention group</td>
<td>The intervention used a pictorial asthma action plan (PAAP) previously used among asthma patients with a low level of education. The PAAP has three columns. The first column indicates that, when a symptom appears, the patients should use their rescue medication in addition to their standard treatment. The second column indicates that when the frequency of use of the rescue medication increases, the patient should take methylprednisolone (16 mg tablet 1 2 a day) for five days and use a proton pump inhibitor prescribed for gastric protection after informing her physician. The third column indicates that in the presence of symptoms after methylprednisolone treatment, the patients should call their physician and present to an emergency department. PAAP was given on top of education, which was also given to the control group.</td>
</tr>
<tr>
<td></td>
<td>Length: not specified</td>
</tr>
</tbody>
</table>
The education material was prepared on slides including illustrations, and the content involved basic mechanism, symptoms of asthma, roles of each medication (symptomatic and preventive medication), administration techniques for any device, signs for exacerbation and environmental control.

Patients were alternately assigned to either the study group or the control group according to their admittance order to the department. Both groups were given an interactive asthma education presented by the same respiratory physician on the same planned day. Baseline assessment was conducted, including ACT (asthma control test) and SGRQ (St. George Respiratory Questionnaire). The tests were applied to every participant before the education head-to-head, and at the first, second and sixth-month follow-ups by telephone interviews were done by the same assessor.

Not specified but potentially in the local language.

Face-to-face/paper-based AAP

6-month

Tailored for the illiterate woman (using images to improve the ability to understanding)

High risk of bias

*Asthma control
Between group difference at 6-month in asthma control test, ACT. Mean (SD)
I: 24.0 (1.0) vs C:23.3 (1.3) P=0.07

Health-related quality of life (QoL)
Between group difference at 6-month in St. George Respiratory Questionnaire, SGRQ. Mean (SD)
I: 53.7 (7.5) vs C:50.3 (7.8), P=0.21

Comment on effectiveness:
There was no significant difference between intervention and control for asthma control and QoL.

Consistently shown as no effect.

*Unscheduled care
Between group difference in the number of visits to the emergency department over the 6m study period. Mean (SD)
I: 0.9 (1.2) vs C:1.8 (2.4), P=0.001

Comment on effectiveness:
A significant difference was seen between control and intervention groups for the number of emergency visits during the study period.

Consistently shown as positive effect.

Poureslami, I. et al. (2012)
Effectiveness of educational interventions on asthma self-management in Punjabi and Chinese asthma patients: a randomised controlled trial

Randomised control study
Canada
## Aim
Explore the effectiveness of different formats of culturally relevant information and its impact on asthma patients' self-management within the Punjabi, Mandarin, and Cantonese communities.

## Eligibility

### Inclusion criteria
Had a physician diagnosis of asthma, used asthma medications daily, were at least 21 years of age, immigrated to Canada within the past 20 years, resided in the Greater Vancouver Area (GVA) during the study period, and spoke Mandarin, Cantonese, or Punjabi.

### Exclusion criteria
Not specified

## Participant Characteristics

### Ethnicity
Minority population (Chinese & Punjabi)

### Type of participant
Patient with asthma

### Age
Age at least 21 years

### Sample size, total (Intervention vs control)
92(22/21/20/22)

### Socio-economic status
Migrants to Canada

### Setting
- Geographical area
  Urban
- Setting
  Tertiary (university-based pulmonary medicine clinic)

## Tools

### Measuring health literacy
- 

### Measuring asthma control
- 

## Intervention characteristics

### Intervention group
The intervention involves the development of educational videos using a community participatory approach. Two videos (knowledge & community) are culturally and linguistically appropriate, including people's views and perceptions about health.

In the knowledge video, scientific information is given, such as asthma symptoms, how to avoid asthma environmental-related and behavioural-related triggers & how to manage an asthma attack. In the community video, community opinions & narratives are used covering the community members' cultural beliefs & practices about asthma and its management using social interactive communication styles. Finally, an educated elder addressed potential misconceptions about asthma, provided correct information on managing asthma, and encouraged early intervention.

Length: not specified

### Control or other group description
A pamphlet is reversed engineered from the knowledge video to use the same content but a different presentation format.
| - Procedure | Eligible subjects are randomly assigned to three experimental groups and view: Grp 1: physician-led knowledge video Grp 2: patient-generated community video Grp 3: Both Videos One comparison group will read: Grp 4: Educational pamphlet Immediately after reviewing the educational materials, the participants are asked to study questionnaire. Questionnaires include knowledge of asthma symptoms, knowledge of asthma triggers & triggers that could make asthma worse, understanding physician instruction on medication use & proper use of an inhaler. Intervention is done at the 1-month point after the pre-test assessment. Follow-up lasted for nine months, where assessments are done pre-intervention and at the 3-month point. Six months post follow up post-test assessment, patients are assessed for their self-management practices |
| - Language used | Punjabi and Mandarin |
| - Mode of delivery | Video-based delivery and face-to-face assessment |
| - Length of intervention | 9-month |
| - Tailoring to health literacy level | The educational materials are developed to align with the health literacy definition by Nutbeam et al. [77] of critical health literacy, where advanced cognitive and social skills are needed to ensure critical analysis of the situation. |
| Risk of bias assessment | High risk of bias |
Outcomes

**Asthma control**
No relevant outcome

**Unscheduled care**
No relevant outcome

* Inhaler technique

*Inhaler technique*: Within group comparison of inhaler technique score at baseline and 3m: Mean (SD) mean difference, MD (95%CI)

<table>
<thead>
<tr>
<th>Group</th>
<th>Baseline</th>
<th>3m</th>
<th>MD (95%CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>4.0 (2.1)</td>
<td>5.9 (2.0)</td>
<td>2.71 (1.35 to 4.06)</td>
</tr>
<tr>
<td>C</td>
<td>4.5 (2.0)</td>
<td>6.8 (2.0)</td>
<td>1.95 (0.99 to 2.91)</td>
</tr>
<tr>
<td>IK+C</td>
<td>3.9 (2.1)</td>
<td>6.8 (1.6)</td>
<td>1.53 (0.66 to 2.40)</td>
</tr>
<tr>
<td>C</td>
<td>4.8 (2.3)</td>
<td>6.6 (1.4)</td>
<td>1.05 (-0.10 to 2.20)</td>
</tr>
</tbody>
</table>

**Comment on effectiveness:**
No between group comparison "Proper use of inhalers improved significantly among all experimental groups over time P< 0.001"

Insufficient details to gauge the effectiveness.

*Knowledge:

*Understanding physician instructions on medication use*: Within group comparison of inhaler technique score at baseline and 3m: Mean (SD) MD (95%CI)

<table>
<thead>
<tr>
<th>Group</th>
<th>Baseline</th>
<th>3m</th>
<th>MD (95%CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>0.8 (0.6)</td>
<td>1.4 (0.8)</td>
<td>0.53 (0.12 to 0.94)</td>
</tr>
<tr>
<td>C</td>
<td>1.2 (0.9)</td>
<td>1.7 (0.9)</td>
<td>0.38 (-0.06 to 0.82)</td>
</tr>
<tr>
<td>IK+C</td>
<td>1.7 (0.8)</td>
<td>1.8 (0.6)</td>
<td>0.24 (-0.19 to 0.66)</td>
</tr>
<tr>
<td>C</td>
<td>1.6 (1.1)</td>
<td>1.7 (0.8)</td>
<td>0.35 (-0.22 to 0.92)</td>
</tr>
</tbody>
</table>

**Comment on effectiveness:**
No between each intervention groups and control group comparison. "There was a significant difference in mean scores in the improvement of knowledge in asthma symptoms, triggers and the understanding of physician instructions on medication use between intervention groups and control" P<0.05

Insufficient details to gauge the effectiveness.

---

**Yin HS et al. (2017)**
Use of a low-literacy written action plan to improve parent understanding of paediatric asthma management: A randomised controlled study.

**Type of study**
Randomised control study

**Country**
United States

**Aim**
Test the efficacy of a low-literacy, plain language, photograph- and pictogram-based asthma action plan in enhancing parent understanding of child asthma management

**Eligibility**

- **Inclusion criteria**
  1) English- or Spanish-speaking parent or primary caregiver of a child diagnosed with asthma aged 2–12 years
  2) Whose child receives asthma care at one of the sites.

- **Exclusion criteria**
  No legal guardian present

**Participant Characteristics**

- **Ethnicity**
  Mixed majority and minority population (Hispanic):
<table>
<thead>
<tr>
<th>Type of participant</th>
<th>Parent of child with asthma</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Mean age 35.5 (8.3)</td>
</tr>
<tr>
<td>Sample size, total (Intervention vs control)</td>
<td>217 (109/108)</td>
</tr>
<tr>
<td>Socio-economic status</td>
<td>Low-income</td>
</tr>
<tr>
<td>The portion of limited health literacy level</td>
<td>69.9% (151/217)</td>
</tr>
<tr>
<td>Baseline asthma control</td>
<td>Mild intermittent (31.3%), persistent (35%) and moderate/severe (33.6%)</td>
</tr>
</tbody>
</table>

Setting

- Geographical area | Urban |
- Setting | Secondary care (two paediatric outpatient clinics) |

Tools

- Measuring health literacy | Newest vital sign (NVS) |
- Measuring asthma control | Not specified |

Intervention characteristics

- Intervention group
  The intervention is a low-literacy, plain language, pictogram-, and photograph-based asthma action plan (AAP). A hypothetical AAP was created involving commonly prescribed medications. The tool focuses on three areas of chronic asthma management recognised as confusing for parents:
  1) medications to give every day even when the child is sick
  2) need for a spacer to maximise medication delivery to lungs
  3) appropriate emergency response.

  The intervention emphasised these key messages by incorporating specific low-literacy techniques such as plain language, pictorial illustrations, photographs, and optimisation of design elements.

  Length: not specified

- Control or other group description
  Parents in the control group received a standard action plan developed by the American Academy of Allergy Asthma & Immunology. The medication regimen for the hypothetical child, Jason, was typed in. In each zone, medications information is filled in by the provider within a table format. All information is presented in text format.

- Procedure
  Parents were randomly assigned to the intervention and control groups. Randomisation was done using sealed envelopes in a block of 50 in each. The lead project coordinator is responsible for the randomisation procedure, but research assistants are blinded to randomisation. Baseline assessments of sociodemographic & asthma-related characteristics are collected before assessment using WAAP. Action plans are presented to parents concealed within a portfolio and instructed not to reveal the action plan to the interviewer.

  Participants were assessed for their knowledge of 1) green zone knowledge 2) Red zone knowledge. Parents are asked to refer to the action plans they were given to answer questions. They are allowed to take as much time as needed to respond.
<table>
<thead>
<tr>
<th>Language used</th>
<th>English and Spanish</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mode of delivery</td>
<td>Face-to-face</td>
</tr>
<tr>
<td>Length of intervention</td>
<td>Immediate assessment</td>
</tr>
<tr>
<td>Tailoring to health literacy level</td>
<td>The level of health literacy among parents is not measured quantitatively. However, the intervention was tailored to the low-literacy status as described by Sheridan et al. [87].</td>
</tr>
</tbody>
</table>

**Risk of bias assessment**
Low risk of bias

**Outcomes**

- **Asthma control**
  No relevant outcome

- **Unscheduled care**
  No relevant outcome

- **Perceived ease of use**
  *Perceived ease of use (PAAP):* Between group comparison of proportion expressing trouble reading the allocated PAAP n (%)  
  I: 93 (85%) vs 93 (88%), p=0.7

  **Comment on effectiveness:**
  No significant between-group difference in proportion expressing trouble reading the allocated PAAP, though when shown both PAAPs 79% considered the low-literacy PAAP easier to understand.

  **Illustrated as consistently no effect**

- **Knowledge**
  *Green/yellow zone knowledge*
  Between group comparison of proportion of carers making errors in the knowledge of which medications to give, n (%)  
  I: 63 (63.0) vs 75(77.3) P=0.03
  Between group comparison of proportion of carers making errors in knowledge of need for spacer use, n (%)  
  I: 14 (14.0) vs 48 (51.1) P<0.001

  *Red zone knowledge*
  Between group comparison of proportion of carers making errors in knowledge of appropriate emergency response, n (%)  
  I: 47 (43.1) vs 52 (48.1) P=0.5

  **Comment on effectiveness:**
  There was a significant between group difference in the knowledge of which maintenance medications to give and knowledge of spacer use, but not in the knowledge of appropriate emergency response.

  **Overall, it has shown a positive effect, but not all outcomes are consistent.**
Appendix 11 The Behaviour Change Wheel (BCW) model mapping exercise [137]

<table>
<thead>
<tr>
<th>Study</th>
<th>Trial components</th>
<th>Reviewer 1</th>
<th>Mapping in matrix</th>
<th>Reviewer 2</th>
<th>Mapping in matrix</th>
<th>Consensus</th>
<th>Mapping in matrix</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Reviewer 1</td>
<td>1. COM-B Capability</td>
<td>Reviewer 2</td>
<td>1. COM-B Capability</td>
<td>Consensus</td>
<td>1. COM-B Capability</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Psychological → Enablement 1.2 Problem solving</td>
<td></td>
<td>Psychological → Enablement 1.2 Problem solving</td>
<td></td>
<td>Psychological → Enablement</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Education → Increasing Knowledge or understanding</td>
<td></td>
<td>Education → Increasing Knowledge or understanding</td>
<td></td>
<td>Education → Increasing Knowledge or understanding</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Capability → Psychological</td>
<td></td>
<td>COM-B Motivation</td>
<td>Persuasion 2.2 Feedback on Behaviour</td>
<td></td>
<td>COM-B Motivation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Enablement → increasing</td>
<td></td>
<td>COM-B Motivation</td>
<td>Reflective</td>
<td></td>
<td>COM-B Motivation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>means to increase</td>
<td></td>
<td>Motivation → Reflective</td>
<td>2.2 Feedback on Behaviour</td>
<td></td>
<td>Motivation → Reflective</td>
</tr>
<tr>
<td></td>
<td></td>
<td>capability beyond education and training and beyond environmental restructuring.</td>
<td></td>
<td>[data from monitored ICS was shared with the participant in a non-judgmental fashion at each visit]</td>
<td></td>
<td>[data from monitored ICS was shared with the participant in a non-judgmental fashion at each visit]</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Motivation → Reflective</td>
<td></td>
<td>Education → Increasing Knowledge or understanding</td>
<td></td>
<td>Education → Increasing Knowledge or understanding</td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Methods</td>
<td></td>
<td>1. COM-B Intervention function</td>
<td></td>
<td>1. COM-B Intervention function</td>
<td></td>
<td>1. COM-B Intervention function</td>
</tr>
<tr>
<td></td>
<td>Electronic monitor was attached to participants’ ICS-containing inhaler and inhaler actuation data were recorded.</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td></td>
<td>Subject met with research coordinator to complete four ‘problem solving (PS)’ sessions facilitated by research coordinators.</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>PS is a four 30-minute session. The individualised intervention has 4 active interactive steps (one per research session).</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td></td>
<td>Step 1: This step consists of defining problem particularly in the aspect of adherence. This motivational technique to help the participant view that occurrence of problems (non-adherence) as inevitable, normal and solvable.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Step 2: This step consists of brainstorming of alternative solutions.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Step 3: This step consists of choosing the best solution by weighing desirable and undesirable consequences.</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Step 4: The chosen solution is then evaluated and revised.</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

Discussion:
1. The differences
   Although both reviewer 1 and 2 agreed to include the aspect of reflective motivation, both reviewers had difference in opinions on the intervention functions to improve the reflective motivation aspect of the components.
2. Consensus
   We agreed that the trial include feedback on behaviour, in this case non-adherence monitored using the actuation of the ICS. Instead of education, the problem-solving session, allows two-way communication of how participants with non-adherence can be persuaded to reflect the problem and work on how to overcome this within their means.
<table>
<thead>
<tr>
<th>Study</th>
<th>Reviewer 1</th>
<th>Reviewer 2</th>
<th>Consensus</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pg.3 (Study protocol) The intervention group viewed a 20-minute asthma educational video entitled “Roxy to the Rescue” before discharge from the ED. This animated program targets urban families with asthmatic children. Key Educational Messages includes: (a) basic facts about asthma, (b) roles of medications, and (c) patient skills.</td>
<td>Capability → Psychological → knowledge or skills; Education → Increasing Knowledge or understanding.</td>
<td>Capability → Physical → Knowledge or skills; Education → 5.1 Information about health consequences [basic facts about asthma; roles of medications].</td>
<td>1. COM-B Capability: Psychological AND 2. Intervention function: Education</td>
</tr>
<tr>
<td></td>
<td>COM-B Capability → Physical → Training → 4.1 Instruction how to perform behaviour &amp; 6.1 Demonstration of the behaviour (indirectly, film).</td>
<td>COM-B Capability → Psychological → Education → 5.1 Information about health consequences [basic facts about asthma; roles of medications].</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Capability → Psychological → Knowledge or skills; Education → Increasing Knowledge or understanding.</td>
<td>Capability → Physical → Knowledge or skills; Education → 5.1 Information about health consequences [basic facts about asthma; roles of medications].</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

**Discussion:**
We agreed on both of the components of the behaviour change model and the intervention functions for this trial. However, the ‘patient skills’ component was not described in the report. We, therefore, don’t really know whether this covered demonstration of behaviour and/or instruction how to perform behaviour.
<table>
<thead>
<tr>
<th>Study</th>
<th>Trial components</th>
<th>Reviewer 1</th>
<th>Reviewer 2</th>
<th>Consensus</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pg.543-544 (Materials &amp; methods) Three types of interventions: 1) knowledge video - scientific information in terms of asthma symptoms, how to avoid asthma environmental-related and behavioural-related triggers (e.g., exposure to chemicals, dust, pollution, foam, as well as smoking, a sedentary lifestyle, and diet behaviours), and how to manage an asthma attack. Smoking cessation, proper diet, and appropriate exercise for adult asthma patients were also emphasized in the knowledge video 2) community video, community opinions and narratives are used, and covered the community members’ cultural beliefs and practices about asthma and its management using social interactive communication styles. In this patient-generated community video, a key informant (an educated elder) addressed the potential misconceptions about asthma management. 3) combination of 1 &amp; 2.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Discussion:
1. The differences
   - For knowledge video, reviewer 1 included the combination of increasing psychological capability through education which reviewer 2 did not. For community video, reviewer 2 included the combination of improvement in reflective motivation through coercion.
2. Consensus
   - In the knowledge video, the effect of smoking, sedentary lifestyle and eating behaviours, improves one’s psychological capability (improving knowledge on health consequences) through education. We agreed to add this aspect for the knowledge video.
   - In the community video, we agreed that persuasion has covered the aspect of communication by asking participants to reflect on beliefs and practices by community elders. Coercion is not suitable, although functions similarly to persuasion, it also to exert mental discomfort or uneasiness by challenging one’s beliefs and practices.
<table>
<thead>
<tr>
<th>Study</th>
<th>Trial components</th>
<th>Reviewer 1</th>
<th>Reviewer 2</th>
<th>Consensus</th>
</tr>
</thead>
<tbody>
<tr>
<td>P.g.424-426</td>
<td>(Methods) The participants were given an interactive asthma education presented by the same, blindfolded respiratory physician, on the same planned day. The education material was prepared on slides including illustrations and the content involved basic mechanism, symptoms of asthma, roles of each medication (symptomatic and preventive medication), administration techniques for any device, signs for exacerbation and environmental control. They were then given the pictorial asthma action plan. The paper-based pictorial asthma action plan has three columns with each column containing instructions with figures for daytime and night-time symptoms. Column 1: Instruction to use of rescue medications in addition to standard treatment when a symptom appears. Column 2: Instruction to take methylprednisolone pills for 5 days and a proton pump inhibitor (prescribed for gastric protection) after information physician when the frequency of the rescue medication increases. Column 3: Instruction to call physician and visit the emergency department, if symptoms persist despite taking the methylprednisolone pills.</td>
<td>Capability → Physical → physical skills; Training → imparting skills.</td>
<td>COM-B Capability → Physical → Training → 4.1 Instruction how to perform behaviour &amp; 6.1 Demonstration of the behaviour (indirectly, illustrations) [Administration techniques for any device].</td>
<td>Capability → Physical → Training → 4.1 Instruction how to perform behaviour AND 6.1 Demonstration of the behaviour (indirectly, illustrations) [Administration techniques for any device].</td>
</tr>
<tr>
<td></td>
<td>Capability → Psychological → knowledge or skills; Education → Increasing Knowledge or understanding.</td>
<td></td>
<td>COM-B Capability → Psychological → Education → 5.1 Information about health consequences [symptoms, roles of medications].</td>
<td>Capability → Psychological → Increasing knowledge on symptoms of asthma, roles of medication, signs of exacerbation &amp; triggers.</td>
</tr>
<tr>
<td></td>
<td>Capability → Psychological → knowledge or skills; Enablement → increasing means to increase capability beyond education and training and beyond environmental restructuring.</td>
<td></td>
<td>COM-B Capability → Psychological → Enablement → 1.4 Action planning [taught use of an action plan].</td>
<td>Enablement → [detail planning in event of daytime &amp; night-time symptoms using action plan].</td>
</tr>
<tr>
<td></td>
<td>Discussion:</td>
<td>1. The differences</td>
<td>Reviewer 1 included the combination of increasing psychological capability through education which reviewer 2 did not.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Consensus</td>
<td>2. Consensus</td>
<td>We agreed that psychological capability through education function was used to increased knowledge on symptoms of asthma, roles of medications and signs of exacerbations &amp; triggers. This combination was added on.</td>
<td>3. COM-B Capability: Psychological 4. Intervention function: Education</td>
</tr>
</tbody>
</table>
### Yin HS et al (2017) [140]

<table>
<thead>
<tr>
<th>Study</th>
<th>Trial components</th>
<th>Reviewer 1</th>
<th>Reviewer 2</th>
<th>Consensus</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>1. COM-B Capability</td>
<td>Psychological [knowledge or skills]</td>
<td>Capability</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Intervention function</td>
<td>Enablement → increasing means to increase capability beyond education and training and beyond environmental restructuring.</td>
<td>Enablement</td>
</tr>
<tr>
<td></td>
<td></td>
<td>COM-B Capability</td>
<td>Psychological</td>
<td>Capability</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Intervention function</td>
<td>Training</td>
<td>Training</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1. COM-B Capability</td>
<td>Psychological</td>
<td>Capability</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Intervention function</td>
<td>Enablement</td>
<td>Enablement</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. COM-B Capability</td>
<td>Psychological</td>
<td>Capability</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. Intervention function</td>
<td>Capability</td>
<td>Capability</td>
</tr>
</tbody>
</table>

**Discussion:**
1. The differences
2. Consensus

There was no clear explanation of whether the participants were trained to use the low-literacy action plan. However, we agreed that action plan tailoring to the literacy need is a form an enablement for people with low literacy to use an action plan.

---

**Note:** Blue highlights indicate areas where decision-making differences exist between reviewers 1 and 2. The subsequent consensus was made based on the agreed discussion (rightmost column).

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Appendix 12 Risk of bias exercise by two reviewers

<table>
<thead>
<tr>
<th>Domain</th>
<th>Reviewer</th>
<th>Reviewers’ Assessment</th>
<th>Reviewer Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Selection bias</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Random sequence generation</td>
<td>RV 1</td>
<td>Low</td>
<td>Subjects were randomised according to a computer-generated algorithm in a 1:1 ratio to either PS (problem-solving) or AE (asthma education)</td>
</tr>
<tr>
<td></td>
<td>RV 2</td>
<td>Low</td>
<td>Randomised according to a computer-generated algorithm in a 1:1 ratio to either PS or AE</td>
</tr>
<tr>
<td>Selection bias</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Allocation concealment</td>
<td>RV 1</td>
<td>High</td>
<td>The research coordinator was not blinded to study groups. The nature of the intervention may not allow allocation concealment.</td>
</tr>
<tr>
<td></td>
<td>RV 2</td>
<td>High</td>
<td>Subjects worked with the same research coordinator for all visits, who delivered either PS or AE by script. Is there risk of knowing study group</td>
</tr>
<tr>
<td>Reporting bias</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Selective reporting</td>
<td>RV 1</td>
<td>Low</td>
<td>A protocol was mentioned. Primary data reported.</td>
</tr>
<tr>
<td></td>
<td>RV 2</td>
<td>Low</td>
<td>Outcomes were reported as per protocol.</td>
</tr>
<tr>
<td>Other bias</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other sources of bias</td>
<td>RV 1</td>
<td>High</td>
<td>Sample size not calculated</td>
</tr>
<tr>
<td></td>
<td>RV 2</td>
<td>Low</td>
<td>No other source of bias found</td>
</tr>
<tr>
<td></td>
<td>RV 3</td>
<td>High</td>
<td>Without sample size calculation, the study is underpowered</td>
</tr>
<tr>
<td></td>
<td>(consensus)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Performance bias</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blinding</td>
<td>RV 1</td>
<td>High</td>
<td>Participants not blinded to study due to the nature of the intervention (delivery of PS)</td>
</tr>
<tr>
<td></td>
<td>RV 2</td>
<td>High</td>
<td>Blinding of participants and research coordinator to study hypothesis was not done</td>
</tr>
<tr>
<td>Detection bias</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blinding</td>
<td>RV 1</td>
<td>High</td>
<td>Blinded were assessed with full awareness of the group they were assigned</td>
</tr>
<tr>
<td></td>
<td>RV 2</td>
<td>High</td>
<td>For the other study outcomes – QOL (quality of life) and ACT (asthma control test) was assessed by participants (participants were not blinded to hypotheses)</td>
</tr>
<tr>
<td>Attrition bias</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Incomplete outcome data</td>
<td>RV 1</td>
<td>Low</td>
<td>Dropouts and exclusions are reported</td>
</tr>
<tr>
<td></td>
<td>RV 2</td>
<td>Low</td>
<td>Pre-enrollment power calculations based on an intention-to-treat (ITT) framework</td>
</tr>
</tbody>
</table>

Macy, ML. et. al (2011)
<table>
<thead>
<tr>
<th>Domain</th>
<th>Reviewer</th>
<th>Reviewers’ Assessment</th>
<th>Reviewer Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Selection bias</strong></td>
<td>RV 1</td>
<td>High</td>
<td>The method of randomisation was stratified based on health literacy level.</td>
</tr>
<tr>
<td>Random sequence generation</td>
<td>RV 2</td>
<td>High</td>
<td>Randomisation was done (block stratified to health literacy and site), but not clear what was used? Computer</td>
</tr>
<tr>
<td><strong>Selection bias</strong></td>
<td>RV 1</td>
<td>Low</td>
<td>Unit of allocation was by the patient in randomisation scheme</td>
</tr>
<tr>
<td>Allocation concealment</td>
<td>RV 2</td>
<td>Low</td>
<td>Random allocation was made at the start of the study.</td>
</tr>
<tr>
<td><strong>Reporting bias</strong></td>
<td>RV 1</td>
<td>High</td>
<td>A protocol was mentioned. Effect of intervention on those with limited health literacy and watching a video was not completed.</td>
</tr>
<tr>
<td>Selective reporting</td>
<td>RV 2</td>
<td>High</td>
<td>Protocol available. Not all results reported, in-text description</td>
</tr>
<tr>
<td><strong>Other bias</strong></td>
<td>RV 1</td>
<td>Unclear</td>
<td>No other bias</td>
</tr>
<tr>
<td>Other sources of bias</td>
<td>RV 2</td>
<td>Unclear</td>
<td>Only needed participant assent and not necessarily written consent</td>
</tr>
<tr>
<td><strong>Performance bias</strong></td>
<td>RV 1</td>
<td>Unclear</td>
<td>The blinding of participants was not described clearly.</td>
</tr>
<tr>
<td>Blinding (participant(s) and personnel)</td>
<td>RV 2</td>
<td>Unclear</td>
<td>Blinding of participants was not reported, e.g., blinded for the hypothesis of the study.</td>
</tr>
<tr>
<td><strong>Detection bias</strong></td>
<td>RV 1</td>
<td>Low</td>
<td>RA was blinded to the intervention/control study arm</td>
</tr>
<tr>
<td>Blinding (outcome assessment)</td>
<td>RV 2</td>
<td>High</td>
<td>The research assistant is the outcome assessor</td>
</tr>
<tr>
<td></td>
<td>RV 3</td>
<td>High</td>
<td>The research assistant is the outcome assessor who enrolled participants to watch the video</td>
</tr>
<tr>
<td><strong>Attrition bias</strong></td>
<td>RV 1</td>
<td>Low</td>
<td>The number of dropouts and reasons are mentioned</td>
</tr>
<tr>
<td>Incomplete outcome data</td>
<td>RV 2</td>
<td>Low</td>
<td>Intention to treat analyses was used and reported</td>
</tr>
</tbody>
</table>

Ozyigit, LP. et al. (2014)
<table>
<thead>
<tr>
<th>Selection bias</th>
<th>RV 1</th>
<th>High</th>
<th>Patients were alternately assigned to either the study group or the control group according to their admittance order to the department.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Random sequence generation</td>
<td>RV 2</td>
<td>High</td>
<td>Participants were not randomised but alternately assigned.</td>
</tr>
<tr>
<td>Allocation concealment</td>
<td>RV 1</td>
<td>High</td>
<td>Concealment may not be possible due to alternate assignment to groups.</td>
</tr>
<tr>
<td></td>
<td>RV 2</td>
<td>High</td>
<td>Unsure how as participants were assigned alternately.</td>
</tr>
<tr>
<td>Reporting bias</td>
<td>RV 1</td>
<td>Low</td>
<td>All outcomes are reported.</td>
</tr>
<tr>
<td>Selective reporting</td>
<td>RV 2</td>
<td>Low</td>
<td>Measuring what mention to measure.</td>
</tr>
<tr>
<td>Other bias</td>
<td>RV 1</td>
<td>High</td>
<td>Sample size not calculated.</td>
</tr>
<tr>
<td>Other sources of bias</td>
<td>RV 2</td>
<td>Low</td>
<td>No other source of bias found.</td>
</tr>
<tr>
<td></td>
<td>RV 3</td>
<td>High</td>
<td>Without sample size calculation, the study is underpowered.</td>
</tr>
<tr>
<td>Performance bias</td>
<td>RV 1</td>
<td>High</td>
<td>Personnel (respiratory physician) was blinded to the intervention and control group. However, the blinding of participants was not possible due to alternate allocation.</td>
</tr>
<tr>
<td>Blinding (participant s and personnel)</td>
<td>RV 2</td>
<td>High</td>
<td>Due to nature of the intervention, blinding of personnel may not be ensured and alternate allocation of participants may compromise blinding of treatment.</td>
</tr>
<tr>
<td>Detection bias</td>
<td>RV 1</td>
<td>High</td>
<td>It was not mentioned whether the same person who provided the education was the same person who assessed the outcome through follow-up phone calls</td>
</tr>
<tr>
<td>Blinding (outcome assessmen t)</td>
<td>RV 2</td>
<td>High</td>
<td>No mention of patient blinded by hypothesis, types of intervention or expected outcome.</td>
</tr>
<tr>
<td>Attrition bias</td>
<td>RV 1</td>
<td>Unclear</td>
<td>Numbers for dropouts for each arm was reported, but reasons for dropouts were not mentioned.</td>
</tr>
<tr>
<td>Incomplete outcome data</td>
<td>RV 2</td>
<td>Unclear</td>
<td>Dropout and reason for drop out were mentioned, but unclear how the analysis was done? including dropouts in the analysis.</td>
</tr>
</tbody>
</table>

Poureslami, I. et al. (2012)

<table>
<thead>
<tr>
<th>Domain</th>
<th>Reviewer</th>
<th>Reviewers’ Assessment</th>
<th>Reviewer Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Selection bias</td>
<td>RV 1</td>
<td>High</td>
<td>Eligible subjects were randomly assigned to one of the three experimental groups.</td>
</tr>
<tr>
<td>Random</td>
<td>RV 2</td>
<td>High</td>
<td>Patients with asthma were assigned at random.</td>
</tr>
<tr>
<td><strong>sequence generation</strong></td>
<td>RV 1</td>
<td>High</td>
<td>The nature of the intervention may not allow complete concealment.</td>
</tr>
<tr>
<td>------------------------</td>
<td>------</td>
<td>------</td>
<td>---------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Selection bias</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Allocation concealment</strong></td>
<td>RV 2</td>
<td>High</td>
<td>Not mentioned how allocation concealment was done.</td>
</tr>
<tr>
<td><strong>Reporting bias</strong></td>
<td></td>
<td>Low</td>
<td>Reporting was it planned to measure</td>
</tr>
<tr>
<td><strong>Selective reporting</strong></td>
<td></td>
<td>Low</td>
<td>Primary outcomes were reported</td>
</tr>
<tr>
<td><strong>Other bias</strong></td>
<td></td>
<td>High</td>
<td>Use of convenience sampling to recruit the participants</td>
</tr>
<tr>
<td><strong>Other sources of bias</strong></td>
<td>RV 2</td>
<td>High</td>
<td>The tool used for measurement: the validity and reliability</td>
</tr>
<tr>
<td><strong>Performance bias</strong></td>
<td></td>
<td>Unclear</td>
<td>Blinding procedure for participants and personnel not described</td>
</tr>
<tr>
<td><strong>Blinding</strong></td>
<td></td>
<td>Unclear</td>
<td>The facilitators were blinded for the hypothesis of intervention but it was not described if the patient was blinded to the hypothesis.</td>
</tr>
<tr>
<td><strong>Detection bias</strong></td>
<td></td>
<td>Unclear</td>
<td>Not described</td>
</tr>
<tr>
<td><strong>Blinding</strong></td>
<td></td>
<td>Unclear</td>
<td>Few of the interventions, e.g., self-reported questionnaire was measured by the participants who are not blinded to the type of group</td>
</tr>
<tr>
<td><strong>Attrition bias</strong></td>
<td></td>
<td>High</td>
<td>Dropouts were not stated from which intervention group and reasons are not reported.</td>
</tr>
<tr>
<td><strong>Incomplete outcome data</strong></td>
<td>RV 2</td>
<td>High</td>
<td>Some data were not mentioned in the text, and no chart to show.</td>
</tr>
</tbody>
</table>

**Yin, HS. et al (2017)**

<table>
<thead>
<tr>
<th><strong>Domain</strong></th>
<th><strong>Reviewer</strong></th>
<th><strong>Reviewers’ Assessment</strong></th>
<th><strong>Reviewer Comments</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Selection bias</strong></td>
<td>RV 1</td>
<td>Unclear</td>
<td>Enrolled parents were randomly assigned to receive either the low-literacy or standard action plan. Randomisation was implemented manually by one of the team members, but it was not mentioned if the personnel involved in the randomisation procedure was involved in the assessment for site 2.</td>
</tr>
<tr>
<td><strong>Random sequence generation</strong></td>
<td></td>
<td></td>
<td>Although the envelope was arranged randomly –how was randomisation achieved – tossing the enveloped? Generation of the sequence by a computer?</td>
</tr>
<tr>
<td>Selection bias Allocation concealment</td>
<td>RV 1</td>
<td>Low</td>
<td>Action plans were presented to parents concealed within portfolios, and parents were instructed not to reveal the concealed action plan</td>
</tr>
<tr>
<td>--------------------------------------</td>
<td>------</td>
<td>-----</td>
<td>----------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td></td>
<td>RV 2</td>
<td>Low</td>
<td>The project lead was responsible for randomisation, and RAs were blinded to randomisation throughout the assessment</td>
</tr>
<tr>
<td>Reporting bias Selective reporting</td>
<td>RV 1</td>
<td>Low</td>
<td>All outcomes are reported</td>
</tr>
<tr>
<td></td>
<td>RV 2</td>
<td>Low</td>
<td>Measuring what mention to measure.</td>
</tr>
<tr>
<td>Other bias</td>
<td>RV 1</td>
<td>High</td>
<td>Recruitment and intervention delivered on the same day.</td>
</tr>
<tr>
<td>Other sources of bias</td>
<td>RV 2</td>
<td>Low</td>
<td>No other source of bias found? coercion considered bias – no time to understand study before recruitment takes place</td>
</tr>
<tr>
<td></td>
<td>RV 3</td>
<td>High</td>
<td>Participation on the same day of recruitment will have a significant bias on the understanding of research &amp; 'true' willingness to participate</td>
</tr>
<tr>
<td>Performance bias Blinding (participants and personnel)</td>
<td>RV 1</td>
<td>Low</td>
<td>Research assistants were blinded to randomisation status throughout the assessments. In addition, study participants were blinded to randomisation assignment until assessments involving the WAAPs were conducted.</td>
</tr>
<tr>
<td></td>
<td>RV 2</td>
<td>Low</td>
<td>participants were blinded until assessments were conducted and asked not to inform the assessor.</td>
</tr>
<tr>
<td>Detection bias Blinding (outcome assessment)</td>
<td>RV 1</td>
<td>Low</td>
<td>Parents were instructed not to reveal the concealed action plan to their interviewer.</td>
</tr>
<tr>
<td></td>
<td>RV 2</td>
<td>Unclear</td>
<td>However, it is not clear who is the assessor could it be the lead investigator who does the randomisation</td>
</tr>
<tr>
<td></td>
<td>RV 3</td>
<td>Low</td>
<td>The assessor was blinded to groups (Procedure)</td>
</tr>
<tr>
<td>Attrition bias Incomplete outcome data</td>
<td>RV 1</td>
<td>Low</td>
<td>For sociodemographic data, one missing data from health literacy measurement and one from asthma severity score were reported. Other sociodemographic and trial data are complete.</td>
</tr>
<tr>
<td></td>
<td>RV 2</td>
<td>Low</td>
<td>Attrition was reported, but there was no attrition after randomisation. (Intervention and measurement of outcome was done within the same session/day)</td>
</tr>
</tbody>
</table>
### Appendix 13 The TIDieR Checklist exercise

**Apter, AJ. et. al (2011)**

Problem solving to improve adherence and asthma outcomes in urban adults with moderate or severe asthma: a randomized controlled trial.

<table>
<thead>
<tr>
<th>Item number</th>
<th>Item number</th>
<th>Item</th>
<th>Where located</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>1.</td>
<td>BRIEF NAME</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Provide the name or a phrase that describes the intervention</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2.</td>
<td>WHY</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Describe any rationale, theory, or goal of the elements essential to the intervention</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3.</td>
<td>WHAT</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Materials: Describe any physical or informational materials used in intervention delivery or in training of intervention providers. Provide information on where the materials can be accessed (e.g., online appendix, URL)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>PS is a four 30-minute session. The individualised intervention has 4 active interactive steps (one per research session).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Step 1: This step consists of defining problem particularly in the aspect of adherence. This motivational technique to help the participant view that occurrence of problems (non-adherence) as inevitable, normal and solvable.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Step 2: This step consists of brainstorming of alternative solutions.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Step 3: This step consists of choosing the best solution by weighing desirable and undesirable consequences.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Step 4: The chosen solution is then evaluated and revised.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4.</td>
<td>Procedures: Describe each of the procedures, activities, and/or processes used in the intervention, including any enabling or support activities</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Providing each of the procedures, activities, and/or processes used in the intervention, including any enabling or support activities</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5.</td>
<td>WHO PROVIDED?</td>
</tr>
</tbody>
</table>
6. **HOW**
   Describe the modes of delivery (e.g., face-to-face or by some other mechanism such as internet or telephone) of the intervention and whether it was provided individually or in a group.

   | Pg. 517 | (Methods) The intervention was delivered via face-to-face and the sessions were done individually. |

7. **WHERE**
   Describe the type(s) of location(s) where the intervention occurred, including any necessary infrastructure or relevant features.

   | Pg. 517 | (Methods) Subjects were recruited from primary care and asthma specialty practices serving low-income inner-city neighbourhoods with a high prevalence of asthma morbidity. |

8. **WHEN AND HOW MUCH**
   Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose.

   | Pg. 517-518 | (Methods) This is a 26-week study. Two weeks after enrolment, participants were randomized to intervention and control group. They were met by the research coordinators monthly for four months to complete 30-minutes ‘problem solving’ sessions. Upon completing this, on monthly basis, they met the research coordinators to download inhalers’ data. |

9. **TAILORING**
   If the intervention was planned to be personalized, titrated or adapted, then describe what, why, when and how.

   | Pg. 517-518 | (Methods) Intervention was delivered according to individual needs and issues with adherence e.g., exploration of own problems during the first session and how to deal with these problems during session 2 and 3. |

10. **HOW WELL**
    Planned: If intervention adherence or fidelity was assessed, describe how and by whom, and if any strategies were used to maintain or improve fidelity, describe them.

    | Pg. 523b | Fidelity to the protocol was then monitored, first by having the researcher-patient interactions observed by project managers in the early stage of the project, and secondly by periodic unannounced observations of visits with participants in the later stages. Procedures and problems were discussed at weekly team meetings with the PI. |

11. Actual: If intervention adherence or fidelity was assessed, describe the extent to which the intervention was delivered as planned.

    | Pg. 523b | In this way 100% fidelity to the protocol was achieved. |

Parental health literacy and asthma education delivery during a visit to a community-based paediatric emergency department: a pilot study.

<table>
<thead>
<tr>
<th>Item number</th>
<th>Item</th>
<th>Primary paper (page or appendix number)</th>
<th>Other details</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>BRIEF NAME</td>
<td>Provide the name or a phrase that describes the intervention</td>
<td>Pg. 3 (Study protocol) “Roxy to the Rescue” asthma education video</td>
</tr>
<tr>
<td>2.</td>
<td>WHY</td>
<td>Describe any rationale, theory, or goal of the elements essential to the intervention</td>
<td>Pg. 2 To compare change in asthma knowledge among parents with low or adequate health literacy after video or written asthma education delivered during their child’s asthma-related emergency department (ED) visit</td>
</tr>
<tr>
<td>Question</td>
<td>Description</td>
<td></td>
<td></td>
</tr>
<tr>
<td>----------</td>
<td>-------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>3. WHAT</strong>&lt;br&gt;Materials</td>
<td>Describe any physical or informational materials used in intervention delivery or in training of intervention providers. Provide information on where the materials can be accessed (e.g., online appendix, URL).&lt;br&gt;&lt;br&gt;(Study protocol) The intervention group viewed a 20-minute asthma educational video entitled “Roxy to the Rescue” before discharge from the ED. This animated program targets urban families with asthmatic children. Key Educational Messages includes: (a) basic facts about asthma, (b) roles of medications, and (c) patient skills.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>4. Procedures</strong>&lt;br&gt;Describe each of the procedures, activities, and/or processes used in the intervention, including any enabling or support activities</td>
<td>Parents completed an orally administered survey about the child’s asthma history, current asthma symptoms, health care utilization, and demographic characteristics. Baseline asthma knowledge and sense of asthma control were assessed. After baseline data collection, parents were randomized to receive either video (intervention) or written (active-control) asthma education materials. Subjects were contacted by telephone, 4 to 6 weeks after study enrolment. At follow-up, the knowledge and sense of control measures were repeated. Subjects also reported on frequency of the child’s asthma symptoms and health care utilization.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>5. WHO PROVIDED?</strong>&lt;br&gt;For each category of intervention provider (e.g., psychologist, nursing assistant), describe their expertise, background and any specific training given</td>
<td>Information not provided</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>6. HOW</strong>&lt;br&gt;Describe the modes of delivery (e.g., face-to-face or by some other mechanism such as internet or telephone) of the intervention and whether it was provided individually or in a group</td>
<td>(Study protocol) The intervention was delivered via video. No details provided whether if any member of the research team was present, whether it was given in groups or individual families.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>7. WHERE</strong>&lt;br&gt;Describe the type(s) of location(s) where the intervention occurred, including any necessary infrastructure or relevant features</td>
<td>(Study setting &amp; population) Emergency Department of Hurley Medical Centre in Flint, Michigan.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>8. WHEN AND HOW MUCH</strong>&lt;br&gt;Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose.</td>
<td>The 20-minute video-based intervention was delivered once at the point of enrolment. Participants were contacted by phone 4 – 6 weeks later for assessment.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>9. TAILORING</strong>&lt;br&gt;If the intervention was planned to be personalized, titrated or adapted, then describe what, why, when and how</td>
<td>(Study protocol) The animated video targets urban families with asthmatic children</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>10. MODIFICATIONS</strong>&lt;br&gt;If the intervention was modified during the course of the study, describe the changes (what, why, when, and how).</td>
<td>Information not provided</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Ozyigit, L. et. al (2014)
The effectiveness of a pictorial asthma action plan for improving asthma control and the quality of life in illiterate women

<table>
<thead>
<tr>
<th>Item number</th>
<th>Item</th>
<th>Where located</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td><strong>BRIEF NAME</strong> Provide the name or a phrase that describes the intervention</td>
<td>Pg.423</td>
</tr>
<tr>
<td>2.</td>
<td><strong>WHY</strong> Describe any rationale, theory, or goal of the elements essential to the intervention</td>
<td>Pg. 424</td>
</tr>
<tr>
<td>3.</td>
<td><strong>WHAT</strong> Materials: Describe any physical or informational materials used in intervention delivery or in training of intervention providers. Provide information on where the materials can be accessed (e.g., online appendix, URL)</td>
<td>Pg.425-426</td>
</tr>
</tbody>
</table>
4. **Procedures:** Describe each of the procedures, activities, and/or processes used in the intervention, including any enabling or support activities

   - Patients were alternately assigned to either the study group or the control group according to their admittance order to the department. Both groups were given an interactive asthma education presented by the same, blindfolded respiratory physician, on the same planned day. The education material was prepared on slides including illustrations and the content involved basic mechanism, symptoms of asthma, roles of each medication (symptomatic and preventive medication), administration techniques for any device, signs for exacerbation and environmental control.

   - The study group was given, in addition, pictorial asthma action plan. Follow-up interviews were conducted by telephone in the first and second month after initial admission. Patients were invited to the outpatient clinic for evaluation of quality of life and asthma control after six months including assessment of non-scheduled hospital or emergency visits and clinical measures.

5. **WHO PROVIDED**
   - For each category of intervention provider (e.g., psychologist, nursing assistant), describe their expertise, background and any specific training given

   - (Methods) Blindfolded respiratory physician.

6. **HOW**
   - Describe the modes of delivery (e.g., face-to-face or by some other mechanism such as internet or telephone) of the intervention and whether it was provided individually or in a group

   - (Methods) The intervention was delivered via face-to-face.

   - No information provided whether the intervention was delivered individually or in groups.

7. **WHERE**
   - Describe the type(s) of location(s) where the intervention occurred, including any necessary infrastructure or relevant features

   - (Methods) Primary care hospital outpatient clinic

8. **WHEN AND HOW MUCH**
   - Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose.

   - (Methods) The intervention was delivered at the point of enrolment.

   - No data provided on how long it takes to teach participants the use of pictorial action plan.

9. **TAILORING**
   - If the intervention was planned to be personalized, titrated or adapted, then describe what, why, when and how

   - (Methods) The pictorial asthma action plan was designed to be easily comprehensible by asthma patients with low level of education.

10. **MODIFICATIONS**
    - If the intervention was modified during the course of the study, describe the changes (what, why, when, and how).

    - Information not provided
<table>
<thead>
<tr>
<th>Item number</th>
<th>Item</th>
<th>Primary paper (page or appendix number)</th>
<th>Other details</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td><strong>BRIEF NAME</strong>&lt;br&gt;Provide the name or a phrase that describes the intervention</td>
<td>Pg.542</td>
<td>(abstract) Culturally relevant knowledge and community education video intervention.</td>
</tr>
<tr>
<td>2.</td>
<td><strong>WHY</strong>&lt;br&gt;Describe any rationale, theory, or goal of the elements essential to the intervention</td>
<td>Pg.542</td>
<td>(abstract) To explore the effectiveness of different formats of culturally relevant information and its impact on asthma patients’ self-management within the Punjabi, Mandarin, and Cantonese communities</td>
</tr>
<tr>
<td>3.</td>
<td><strong>WHAT</strong>&lt;br&gt;Materials: Describe any physical or informational materials used in intervention delivery or in training of intervention providers. Provide information on where the materials can be accessed (e.g., online appendix, URL)</td>
<td>Pg.543-544</td>
<td>(Materials &amp; methods) Three types of interventions: 1) knowledge video - scientific information in terms of asthma symptoms, how to avoid asthma environmental-related and behavioural-related triggers (e.g., exposure to chemicals, dust, pollution, foam, as well as smoking, a sedentary lifestyle, and diet behaviours), and how to manage an asthma attack. Smoking cessation, proper diet, and appropriate exercise for adult asthma patients were also emphasized in the knowledge video 2) community video, community opinions and narratives are used, and covered the community members’ cultural beliefs and practices about asthma and its management using social interactive communication styles. In this patient-generated community video, a key informant (an educated elder) addressed the potential misconceptions about asthma management. 3) combination of 1 &amp; 2.</td>
</tr>
<tr>
<td>4.</td>
<td>Procedures: Describe each of the procedures, activities, and/or processes used in the intervention, including any enabling or support activities</td>
<td>Pg.545</td>
<td>(Materials &amp; methods) Eligible subjects were randomly assigned to one of the three experimental groups (Group 1 viewed a physician-led knowledge video, Group 2 viewed the patient-generated community video, and Group 3 viewed both the knowledge and community videos) and one comparison group (Group 4), which read an educational pamphlet only.</td>
</tr>
</tbody>
</table>

Poureslami, I. et. al (2012)<br>Effectiveness of educational interventions on asthma self-management in Punjabi and Chinese asthma patients: a randomized controlled trial
<table>
<thead>
<tr>
<th>Item</th>
<th>Description</th>
</tr>
</thead>
</table>
| 5. | **WHO PROVIDED**  
For each category of intervention provider (e.g., psychologist, nursing assistant), describe their expertise, background and any specific training given.  
(Pg. 544)  
(Materials & methods) The intervention was delivered by community facilitators whose expertise, background and training were not mentioned. |
| 6. | **HOW**  
Describe the modes of delivery (e.g., face-to-face or by some other mechanism such as internet or telephone) of the intervention and whether it was provided individually or in a group.  
(Pg. 542)  
(Materials & methods) The intervention lasted for 9 months. This process included an initial pretest assessment, followed by a 1-month educational intervention (the patient watched the videos or read the pamphlet based on the study group they belonged to), and was then followed by a 3-month follow-up post-test assessment. |
| 7. | **WHERE**  
Describe the type(s) of location(s) where the intervention occurred, including any necessary infrastructure or relevant features.  
(Pg. 543)  
(Materials & methods) The interventions took place in a convenient place for the patient—either at their home or in our clinic (university-based pulmonary medicine clinic). |
| 8. | **WHEN AND HOW MUCH**  
Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose.  
(Pg. 545)  
(Materials & methods) We conducted our intervention 1 month immediately after the pre-test, and then had a further follow-up 3 months post-intervention. Furthermore, 6 months after the post-intervention, the patients were invited to participate in a telephone follow-up survey to assess their self-reported use of the peak flow meter, whether they followed their action plans, and whether they used their prescribed medications regularly. |
| 9. | **TAILORING**  
If the intervention was planned to be personalized, titrated or adapted, then describe what, why, when and how.  
(Pg. 543)  
(Materials & methods) The intervention was developed through community participatory approach. As a result, the videos are culturally and linguistically appropriate. |
| 10. | **MODIFICATIONS**  
If the intervention was modified during the course of the study, describe the changes (what, why, when, and how).  
-  
Information not provided |
| 11. | **HOW WELL**  
Planned: If intervention adherence or fidelity was assessed, describe how and by whom, and if any strategies were used to maintain or improve fidelity, describe them.  
-  
Information not provided |
| 12. | Actual: If intervention adherence or fidelity was assessed, describe the extent to which the intervention was delivered as planned.  
-  
Information not provided |

Yin HS et. al (2017)  
Use of a low-literacy written action plan to improve parent understanding of paediatric asthma management: A randomized controlled study.
<table>
<thead>
<tr>
<th>Item number</th>
<th>Item</th>
<th>Description</th>
<th>Page</th>
<th>Other details</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>BRIEF NAME</td>
<td>Provide the name or a phrase that describes the intervention</td>
<td>Pg. 919</td>
<td>(Abstract) Low-literacy asthma action plan</td>
</tr>
<tr>
<td>2.</td>
<td>WHY</td>
<td>Describe any rationale, theory, or goal of the elements essential to the intervention</td>
<td>Pg. 920</td>
<td>(Introduction) To test the efficacy of a low-literacy, plain language, photograph- and pictogram-based asthma action plan in enhancing parent understanding of child asthma management</td>
</tr>
<tr>
<td>3.</td>
<td>WHAT</td>
<td>Materials: Describe any physical or informational materials used in intervention delivery or in training of intervention providers. Provide information on where the materials can be accessed (e.g., online appendix, URL)</td>
<td>Pg. 920-921</td>
<td>(Methods) The study intervention was a low-literacy, plain language, pictogram-, and photograph-based asthma action plan. The tool focuses on three areas of chronic asthma management recognized as being confusing for parents/patients, specifically, knowledge of: (1) medications to give, in particular, understanding the need for everyday preventive medications even when the child is sick; (2) need for spacer use to maximize medication delivery to the lungs; and (3) appropriate emergency response (e.g., giving rescue medication right away and seeking medical help). The intervention emphasized these key messages by incorporating specific low-literacy techniques including the use of plain language, pictorial illustrations, photographs, and optimization of design elements (e.g., layout, text design, colour)</td>
</tr>
<tr>
<td>4.</td>
<td>Procedures</td>
<td>Describe each of the procedures, activities, and/or processes used in the intervention, including any enabling or support activities</td>
<td>Pg. 920</td>
<td>(Methods) Parents with children with asthma were enrolled from 2 sites. Parents give consent for participations. Interviews were conducted in Spanish/English according to preference of parents. Eligible parents were randomised using sealed envelopes arranged in blocks of 50 in each site (random order; 25 interventions, 25 control) Lead project coordinator was responsible for the randomisation but RA was blinded to randomisation status. Parents were blinded to randomisation until assessments involving intervention were conducted. Action plans were given in concealed portfolio and were instructed not to reveal the action plan to the interviewer.</td>
</tr>
<tr>
<td>5.</td>
<td>WHO PROVIDED</td>
<td>For each category of intervention provider (e.g., psychologist, nursing assistant), describe their expertise, background and any specific training given</td>
<td>Pg. 920</td>
<td>(Methods) Parents were interviewed by RA’s who are blinded to randomization status of parents. Expertise, background and training for intervention provider was not mentioned</td>
</tr>
<tr>
<td>6.</td>
<td>HOW</td>
<td>Describe the modes of delivery (e.g., face-to-face or by some other mechanism such as internet or telephone) of the intervention and whether it was provided individually or in a group</td>
<td>Pg. 920</td>
<td>(Methods) Intervention was given within concealed portfolio and assessment of knowledge of the action plans was done face-to-face.</td>
</tr>
<tr>
<td>7.</td>
<td>WHERE</td>
<td>Describe the type(s) of location(s) where the intervention occurred, including any necessary infrastructure or relevant features</td>
<td>Pg. 920</td>
<td>(Methods) Subjects were enrolled through paediatric outpatient clinics at two sites.</td>
</tr>
<tr>
<td></td>
<td>WHEN AND HOW MUCH</td>
<td>Pg. 921</td>
<td>(Methods) At point of assessment, parents were assessed on their knowledge based on the asthma action plan. Parents were asked to refer to the action plan they were given to answer questions and were allowed as much time as they needed to respond to each question. No other meeting thereafter.</td>
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<tr>
<td>8.</td>
<td>Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose.</td>
<td></td>
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<tr>
<td>9.</td>
<td>TAILORING</td>
<td>Pg. 920-921</td>
<td>(Methods) The low-literacy action plan was carefully developed in collaboration with parents and health care providers, with input from individuals with expertise in asthma management, health literacy, and cognitive science.</td>
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<tr>
<td></td>
<td>If the intervention was planned to be personalized, titrated or adapted, then describe what, why, when and how.</td>
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<tr>
<td>10.</td>
<td>MODIFICATIONS</td>
<td></td>
<td>Information not provided</td>
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<tr>
<td></td>
<td>If the intervention was modified during the course of the study, describe the changes (what, why, when, and how).</td>
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<td>11.</td>
<td>HOW WELL</td>
<td></td>
<td>Information not provided</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Planned: If intervention adherence or fidelity was assessed, describe how and by whom, and if any strategies were used to maintain or improve fidelity, describe them</td>
<td></td>
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<tr>
<td>12.</td>
<td>Actual: If intervention adherence or fidelity was assessed, describe the extent to which the intervention was delivered as planned.</td>
<td></td>
<td>Information not provided</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 14 Part of the qualitative study’s findings was published in Health Expectation

Insights into how Malaysian adults with limited health literacy self-manage and live with asthma: A Photovoice qualitative study

Hani Salim MMed(Family Medicine), Doctor1,2 | Ingrid Young PhD, Doctor3 | Ping Yen Lee MMed(Family Medicine), Professor4 | Sazlina Shariff-Ghazali PhD, Professor3,5 | Hilary Pinnock MD, Professor1,6 on behalf of RESPIRE collaboration

Abstract

Background: Adjusting to life with a chronic condition is challenging, especially for people with limited health literacy, which is associated with low compliance with self-management activities and poor clinical outcomes.

Objective: We explored how people with limited health literacy understand asthma and undertake self-management practices.

Design: We adopted the arts-based qualitative methodology Photovoice.

Setting and Participants: We sampled ethnically diverse adults with asthma and limited health literacy from four primary healthcare clinics in Malaysia. After a semistructured in-depth interview, a subset of participants took part in the Photovoice component in which participants undertook a 2-week photo-taking activity and subsequent photo-interview. Interviews, conducted in participants’ preferred language, were audio-recorded, transcribed verbatim, translated and analysed thematically. We used the Sorensen’s framework (Domains: access, understand, appraise, apply) to describe participants’ experience of living with asthma, what they understood about asthma and how they decided on self-management practices.

Results: Twenty-six participants provided interviews; eight completed the Photovoice activities. Participants with limited health literacy used various sources to access information about asthma and self-management. Doctor–patient communication had a pivotal role in helping patients understand asthma. The lack of appraisal skills was significant and experiential knowledge influenced how they applied information. Self-management decisions were influenced by sociocultural norms/practices, stigmatizing experiences, and available social support.
Conclusion: Locally tailored multilevel interventions (interpersonal, health system, community and policy) will be needed to support people with limited health literacy to live optimally with their asthma in an ethnically diverse population.

Patient/Public Contribution: Patients were involved in the study design, recruitment, analysis and dissemination.

Keywords
asthma, health literacy, low- and middle-income country, Photovoice, qualitative, supported self-management

1 | BACKGROUND

Limited health literacy is a global public health problem that limits people’s ability to self-manage chronic conditions such as asthma. Health literacy is defined as a person’s cognitive and functional abilities to respond to the healthcare system’s demands to care for their health. About two-thirds of people with asthma in a Malaysian population were found to have limited health literacy. In people with asthma, studies have shown that limited health literacy is associated with increased uncontrolled emergency visits and hospitalizations. Support for self-management in the form of regular healthcare professional reviews and a written action plan improves asthma outcomes. As recommended in asthma guidelines, self-management requires a good understanding of asthma and the ability to implement and/or support in many health settings. Tailoring self-management support for people with limited health literacy is crucial but is rarely provided.

Asthma affects almost 360 million globally, yet it is a neglected noncommunicable disease in many health settings. In Malaysia, the prevalence of adult asthma was 4.2%, with 1.2% of deaths related to asthma in 2009. To date, qualitative explorations on asthma and health literacy issues are mainly from high-income countries. A mismatch between patients’ and doctors’ expectations are among the challenges faced by people with limited health literacy. Other identified barriers include the doctor’s communication style, language and mistrust in the doctor–patient partnership due to perceived racial bias and lack of cultural sensitivity. Culture, health beliefs and experiential knowledge influenced self-management behaviors leading to actions that may not align with evidence-based practice. Individual choices and health decision-making are governed by deeply embedded sociocultural norms and practices within a community. In this study, we recognized the sociocultural diversity of the population in Malaysia and the need to allow creative ways to explore health literacy, asthma and self-management practices. Photovoice, an arts-based qualitative methodology that employs collective conversations, to understand the issues and strengths of the community and the health system. We adopted Photovoice by combining qualitative interviews and photo-taking activities to explore experiences and employ innovative approaches to disseminating the voice of the community. We aimed to explore how people with limited health literacy in Malaysia understand asthma and decide on self-management practices.

2 | METHODS

Ethical approval was granted by the Medical Research and Ethics Committee of the Ministry of Health, Malaysia (ID: NMRR-15-2113-42322) and sponsorship approval by the Academic and Clinical Central Office for Research & Development at the University of Edinburgh (ACCORD ID: AC18113). Informed consent was obtained before participation.

3 | STUDY DESIGN

We adapted Photovoice, an arts-based qualitative methodology (Figure 1) to generate understandings of health literacy challenges among people with asthma in Malaysia. The study included four stages. Stage 1 involved one-to-one interviews. Stage 2 involved training and photo-taking activity. Stage 3 involved one-to-one Photovoice discussions with the subset of participants who took photos. A small-scale exhibition and sharing of findings through local social media networks took place at the end of the study to amplify people’s experiences living with asthma among stakeholders. (Stage 4). Wang’s classic Photovoice description was of a one-way process where recruited participants underwent training, photo-taking activities and discussion as a group. Although participants were given the freedom to take the photographs as individuals, only key photographs were chosen and discussed in focus group discussions. The first group engagement was to train in Photovoice technique and understand the research assignment followed by group dialogue with policy-makers using key photographs. Wang and Burris completed the Photovoice stage with a final participants’ evaluation of the process. We adopted this process to conform to our population’s sociocultural needs. We introduced an in-depth interview in the first stage as a strategy to secure initial engagement, to foster relationships and trust among the research participants. We invited interviewees to take photographs and discussed all their photographs in a confidential interview.
On-going engagement for data analysis, member checking and discussion

Initial in-depth interviews (STAGE 1) n=26

Photo-training and photo-taking activity (STAGE 2) n=12

Photovoice interviews where individuals contextualise all photographs through stories (STAGE 3) n=8

Codification of transcripts and analysis of themes between individual initial interviews and photovoice interviews and across all interviews.

Photo-exhibition of key photographs and dialogues with stakeholders. (STAGE 4)

Repeat loop for each patient!

FIGURE 1 Our adapted Photovoice process

DATA COLLECTION (6 months) ➔ DATA ANALYSIS ➔ DISSEMINATION

TABLE 1 Multicultural Malaysia and the health system

<table>
<thead>
<tr>
<th>The health system</th>
<th>Multicultural and multilingual Malaysia</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Malaysia has both public and private healthcare systems.</td>
<td>• Malaysia is a multicultural country comprising three main ethnic groups: Malay, Chinese and Indians, each with their own culture and language.</td>
</tr>
<tr>
<td>• The Government heavily funds the public health sector through taxation. The private sector is a ‘fee for service’ model often covered by insurance policies.</td>
<td>• The national language, Malay, is used as the main medium of instruction in both primary and secondary national schools.</td>
</tr>
<tr>
<td>• The Government provides primary, secondary and tertiary care for the population. National Referral Centres provide specialized care and support the primary care service.</td>
<td>• English is learnt as a second language.</td>
</tr>
<tr>
<td>• In the public health sector, services are free with copayment ranging from MYR 1-500 to MYR 3500 per day of admission.</td>
<td>• At the primary school level, schools may also offer Mandarin and Tamil mediums of instruction.</td>
</tr>
</tbody>
</table>

3.1 Setting, recruitment and sample

The study was conducted in 2019 at four public health clinics in Klang District, a rural region of Malaysia (see Table 1 for a description of Malaysia’s healthcare system). These clinics were chosen to reflect a range of urban and rural communities, enabling the recruitment of a broad range of participants. Pictorial advertisements and easy-read information about the study were placed at the study sites. H.S. explained the study procedures to potentially interested patients (face-to-face or through phone calls) and assessed eligibility. Video information sheets helped potential participants, regardless of reading ability, visualize the research process, understand what was involved and make an informed decision about participation. The video was made available online where participants could watch it in their own time [https://www.ed.ac.uk/health-literacy/health-literacy-see-and-learn](https://www.ed.ac.uk/health-literacy/health-literacy-see-and-learn) before they gave written consent.

Adult patients aged ≥18 years who had physician-diagnosed asthma on treatment from any of the four clinics, and with limited health literacy (defined as <30 on the validated Malay version of health literacy scale [HLS]) 37, were purposively recruited. A maximum variation sample of participants based on demographics (age, gender, ethnicity) and asthma control assessed using the asthma control questionnaire (ACQ) 32. For those who agreed to participate, an initial interview was arranged at the most convenient clinic for the patient.

3.2 Data collection

Written informed consent was obtained before each activity. In Stage 1, the participant was invited for an initial in-depth, semistructured interview. Using a topic guide (Supporting Information Appendix S1), the interviews started with a general discussion about personal experiences living with asthma. We then explored key areas of interest concerning participants’ experiences of living with and managing asthma within and outside the home and interactions with healthcare professionals. H.S. a Malaysian family physician who designed the study in discussion with the wider research group, conducted all the interviews, assisted by an interpreting. T.P. interviews were conducted in Malay, English, Tamil or Mandarin according to participants’ preference, and they could move between languages if they so wished.

The photo-taking activity (Stages 2 and 3) was offered to all participants at the end of the initial interview—there was no selection
by the researcher at this stage. Those who agreed were given a 30-min training on using a disposable camera and the ethics of photo-taking (i.e., asking permission to take photographs of others). H. S. also provided a guide on using a disposable camera and how to take care of it. Each participant who agreed to photo-taking was given a disposable camera containing 27-picture film to complete the 2-week activity. Participants were given a broad remit about photographs of interest (Table 2) and an infographic around photo-taking rules (Supporting Information Appendix S2).

H. S. arranged for film development, digitizing and printing photographs from returned cameras in preparation for Stage 3 interviews. All the Photovoice interviews, H. S. displayed the photographs in hardcopy format and asked participants to choose the consent they wished to apply to each photograph. There were three options: (i) the photograph may be shared with the researcher and reproduced in publications with a caption of their choosing; (ii) the photograph (hardcopy form) may be shared with the researcher but not reproduced; and (iii) the photograph may not be shared with the researcher or reproduced (these were destroyed). This process allowed participants to understand the implications of allowing reproductions and to reflect and choose photographs they wished to share.

H. S. started the Photovoice interview using the photographs that the participant had agreed to share with the researcher, one at a time. Participants were encouraged to describe where, why the photographs were taken and what it meant to them personally in the context of living with asthma. During the interview, participants were asked if there had been any situations they decided not to capture during the photo-activity. H. S. encouraged participants to explain the reason behind these decisions (or why they decided not to share specific photographs with the researcher), though they were free not to explain their decision. The absence of these photographs challenged participants to reflect on pertinent—but hidden—issues such as social norms and practices. Participants were given space to add an explanation or accompanying text for each photograph. All interviews (in-depth interviews and Photovoice interviews) were digitally audio-recorded using an encrypted audio-recorder.

3.3 | Data analysis

Recorded interviews were transcribed verbatim in the original language, checked for quality and accuracy and anonymized before translation into English using back-to-back translation methods.22 Where it was not possible to translate metaphors, idioms, or culturally specific expressions into English, the original language was maintained and explanatory footnotes provided.22,23 Table 3 describes steps for data analysis.

3.4 | Patient and public involvement (PPI)

The research was discussed with PPI panels in Malaysia and the Asthma UK Centre for Applied Research (AUKCAR).2 They reviewed research documents (participant information sheet and consent forms, animated videos to overcome literacy problems, flyers and photo-taking guidelines) to improve readability and clarity. H. S. spoke with two PPI colleagues to learn more about how people with asthma view research and to discuss the topic guide. For example, one member suggested using common local terms to describe difficulty in breathing, such as “smog” for Malay participants. One of the PPI colleagues piloted the photo-taking activity and made some practical suggestions (e.g., allowing 2-week for the photo-taking activity instead of 1).

<table>
<thead>
<tr>
<th>TABLE 3</th>
<th>Steps taken for data analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>The analysis of the transcripts and the photographs were iteratively informed, but not restricted, by the health literacy framework by Sorensen.</td>
</tr>
<tr>
<td>2.</td>
<td>All the transcripts from the initial in-depth interviews and photo-interviews were uploaded in the computer-aided qualitative analysis software (Nvivo 15).</td>
</tr>
<tr>
<td>3.</td>
<td>After reading and re-reading the in-depth data, H. S. conducted a preliminary analysis, which was then explored with I. V. P. Y. L./S. S. G./H. P.</td>
</tr>
<tr>
<td>4.</td>
<td>H. S. then deductively coded the transcripts using the concerning asthma related-health information: access, understand, appraise and apply.</td>
</tr>
<tr>
<td>5.</td>
<td>Each interview statement was coded into one of the broad themes of Sorensen’s health literacy framework.</td>
</tr>
<tr>
<td>6.</td>
<td>We added additional categories to each theme to ensure we captured unique themes and conforming/nonconforming concepts against the initial assumptions about health literacy.</td>
</tr>
<tr>
<td>7.</td>
<td>Refinement agreement of categories and subsequent themes were done in iterative discussion with the multidisciplinary research team (E. Y. P. Y. L./S. S. G./H. P.), providing diverse clinical, health system and social research backgrounds.</td>
</tr>
<tr>
<td>8.</td>
<td>The teams identified and structured the themes presented in this article. We discussed preliminary analysis and captions accompanying the photographs with the participants enabling additional or discordant themes to emerge.</td>
</tr>
</tbody>
</table>
3.5 | Trustworthiness, reflexivity and power dynamics of research

As researchers, we significantly impact on how data are collected, shaped and analysed. Trustworthiness refers to the degree of confidence in data interpretation and methods used to ensure the quality of a study.²⁷ We adapted the Lincoln and Guba (1985, 1989) criteria to evaluate the credibility, transferability, dependability and confirmability of our qualitative work.²⁸²⁹ We provide a detailed description of the strategies used in Supporting Information Appendix S3 with a summary in Table 4.

4 | RESULTS

4.1 | Description of data set

In total, 36 participants completed the initial interviews, 12 agreed to the photo-taking training session, but only eight completed the photo discussion. Table 5 summarises the participants' characteristics. Reasons for nonparticipation for Stages 2 and 3 included time constraints and hospitalization for a severe exacerbation. Most (23/26) had uncontrolled asthma based on asthma control screening.

4.2 | Presentation of findings

We describe participants’ understanding of asthma and how they decided on self-management practices based on the four domains of health literacy: (i) access; (ii) understand; (iii) appraise; and (iv) apply. For each domain, we report the themes and subthemes that influenced participants’ engagement with health service support for asthma self-management. See Table 6 for a summary. Figure 1 are the photographs taken by the participants, which are related to many of the quotes.

4.3 | Access to information on asthma and self-management

Participants described two sources of information regarding asthma and self-management practices. The primary formal source of information was healthcare professionals. Participants considered the doctors had a duty to share information about asthma, its treatment and how to care for it at

<p>| TABLE 4 | Summary of trustworthiness, reflexivity and power dynamics²⁷²⁸²⁹ |
|-------------------------------|-------------------|-------------------------------|</p>
<table>
<thead>
<tr>
<th>Trustworthiness criteria</th>
<th>Research strategy</th>
<th>Techniques to ensure trustworthiness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Credibility</td>
<td>1. Field notes/note</td>
<td>1. Prolonged engagement</td>
</tr>
<tr>
<td>Transferability</td>
<td>2. Tape recorder</td>
<td>2. Member checking</td>
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<tr>
<td>Dependability</td>
<td>3. Auditing preliminary theses/analysis</td>
<td>3. Peer review</td>
</tr>
<tr>
<td>Conformability</td>
<td>1. Field notes/note</td>
<td>4. Reliability</td>
</tr>
<tr>
<td>Reliability and power</td>
<td>2. Tape recorder</td>
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<tr>
<td>dynamics</td>
<td>3. Auditing preliminary theses/analysis</td>
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</table>

Researchers from different settings: The RESPiRE Global Health Unit was funded by the National Institute of Health Research (NIHR) United Kingdom (UK).

Researchers’ participants’ relationship: Unequal power may make it challenging to elicit descriptions of social practices, explore personal issues such as identities and understand how adults with limited health literacy live with asthma.

H. S. was introduced as a doctor and researcher by a local community leader, or via their doctors enhancing trust in sharing information with H. S. Also, at the photo interview, H. S. was known to participants from the previous interview. The photo activities shifted power to the participant as their choice of photos determined the topics of conversation.

[Appendices] 402
home. Doctors were perceived as health experts and trustworthy sources of information. Reliance on healthcare professional advice overcame participants lack of confidence in finding and interpreting reliable information.

When the doctor explains, I listen to what he has to explain about asthma and the medications because he’s the expert. If I don’t listen, I’ll miss the things that I don’t know, or I’m not sure of. I have to listen carefully to the doctor because I don’t know where else to learn about these. I’m afraid, on my own. I may read the wrong information. I only depended on what the doctor told me; (63-year-old, Malay, woman)

Other sources of formal information were asthma-related pamphlets and health talks. Participants described these sources as helping augment the knowledge shared by their doctors about asthma and how to care for it (Figure 2C).

I like to keep the pamphlets (showing a photograph) on how to use the inhaler from the health clinics. And sometimes, I’ll go to the (health) talks. The content is similar to what the doctor told me, but, the pamphlets and the talks remind me of what I should always do to take care of my asthma, especially at home. It’s like revision (chucked). (51-year-old, Malay, woman)

Informal sources of information about asthma and self-management practices also played an important role especially

<table>
<thead>
<tr>
<th>TABLE 5 Characteristics of participants</th>
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<tbody>
<tr>
<td>Profile</td>
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<td>------------------</td>
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<tr>
<td>Sex</td>
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<td></td>
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<tr>
<td>Age category (years), mean age = 48.6</td>
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<tr>
<td>Self-assigned ethnicity</td>
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<td></td>
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<tr>
<td>ACQ score&lt;sup&gt;1&lt;/sup&gt;</td>
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<td></td>
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<tr>
<td>Health literacy score&lt;sup&gt;2&lt;/sup&gt;</td>
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</tbody>
</table>

Abbreviation: ACQ, asthma control questionnaire.
<sup>1</sup>Score less than 0.75 = well-controlled.
<sup>2</sup>Mean less than 33 = limited health literacy.

<table>
<thead>
<tr>
<th>TABLE 6 Summary of how participants understand asthma and decide on self-management practices</th>
</tr>
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<tbody>
<tr>
<td>Domain of health literacy&lt;sup&gt;3&lt;/sup&gt;</td>
</tr>
<tr>
<td>----------------------------------------</td>
</tr>
<tr>
<td>1. Access to information on asthma and self-management</td>
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<td></td>
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<tr>
<td>2. Understanding information on asthma and self-management</td>
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<td>3. Appraisal of information on asthma and self-management</td>
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<tr>
<td>4. Application of information on asthma and self-management practices</td>
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<sup>3</sup>Domain of health literacy as proposed by Usherwood and colleagues.
recommendations from family members who had asthma. For instance, a participant described the pathophysiology of asthma based on what his sister shared with him:

I think I know why I get these attacks. My windpipe may be blocked because it swells up, probably when I'm allergic to something. So, the swelling closes the windpipe, so my breathing becomes terrible. My sister told me about this; she has asthma too. It takes longer than I do. (33-year-old, Malay, man)

For those who had had asthma since childhood, parents were a source of knowledge about asthma and how to care for it. (Figure 2f)

I searched Facebook [10] to see how people talk about their asthma. I like when they talk about what they cannot eat, see if it's the same issue [as me]. What they used when [their] breathing becomes not that good. I learnt from them. (25-year-old, Chinese, woman)

4.3.1 Understanding Information on Asthma and Self-management

Participants described how both patient and healthcare professional factors influenced the process of understanding information once they had found relevant asthma/health information.

The language used was identified as a key issue. Participants pointed out that paper-based information provided at the healthcare centers was mostly in Malay or English. Although most could read Malay, some struggled to understand these languages and described the need for services and asthma information packs in their native language to help them with their asthma care. One participant expressed her need for Mandarin-version written...
information as she struggled to read Malay and had to ask for help with translation.

It [will] be good if there’s Mandarin version of this action plan. It’ll make my life easier. If the doctor speaks to me in Bahasa (Malay language), I can understand a little bit. But, reading this [the asthma action plan] in Bahasa, I don’t quite understand. I have to ask my husband’s help to translate. (22-year-old Chinese, woman)

Other participants used internet tools such as Google translate to interpret the information given to them. Even amongst participants who were able to read and speak colloquial Malay, some described difficulty understanding the formal Malay language used in asthma information. One participant, for instance, described the written asthma action plan as wordy and difficult to understand.

I can speak and read Malay [language], but the asthma action plan has too many words (chuckled). (78-year-old Chinese, man)

Healthcare professionals were vital in facilitating an understanding of adherence to medication and the evidence-based definition of asthma control. The lack of effective doctor-patient communication—verbal and nonverbal—was a central theme. For example, one participant described how doctors’ lack of explanation made him question the treatment prescribed to him.

They [the doctors] say do this, and that, but they don’t even explain why. They said I have asthma and that I need to use the bronchi inhaler every day, but why? If I’m not sick, why should I use it? (66-year-old, Malay, man)

Some participants recalled their struggles to understand the conversation with their doctors and their asthma care plan because of medical jargon.

Doctors use many words I cannot understand, and I think those are English or it’s scientific words? I’m not sure. Please use the language we ordinary people can understand. (41-year-old, Malay, woman)

Some participants observed nonreceptive body language from their healthcare professional, which detracted their efforts to clarify understanding information about asthma or the management plan.

When I came for follow up, the doctor barely looked at me. That’s not really welcoming. I don’t think that doctor is the type who wants to explain anything to me, so, even if I don’t understand anything, I’ll just keep quiet. (61-year-old Malay, woman)

4.3.2 | Appraisal of information on asthma and self-management

Most participants did not explicitly evaluate information or check with healthcare services to help them appraise information before applying it. When prompted, many participants stated that they had not thought of assessing the information given to them; they ‘just followed’. A participant revealed a paternalistic culture she experienced, which led to such behaviour. She recalled.

I have been an asthma patient for the past 25 years. For many years, I take the medicines prescribed by the clinic. I do what I was told to. I don’t question about right or wrong (on) anything the doctor tells me. I once asked [the doctor] about my breathing. I can’t remember what exactly it was, but his words are deeply engraved in my head: are you the doctor, or I am? I don’t go to school, you see (trying to cover part of her face with her arm). I was embarrassed and [I think, I made a fool of myself by questioning him]. It was many years ago. I know they are nicer now, they really are, but since then, I never asked or questioned. So, I just follow. (62-year-old, Indian, woman)

Other than health information given by the healthcare professionals, information was typically assessed against their experience of living with asthma. For example, a participant highlighted how she weighed up the information about asthma triggers that she had found on social media and related this to her own experience before acting on the information (Figure 7c).

If I see posts on social media and everyone else agreed on it, then probably it’s true. People said that the air-conditioning system in the car makes people cough. It’s the same with me. But, I still use it at times. Like during the haze, showing a photograph, you cannot even see the sun, meaning it’s awful. So, I must [switch on the air-con] (air-conditioning system) and rolled up my car’s window. My asthma with haze is worse than with the air-con. So, I have to choose the lesser evil. But one person is different from another, so you need to understand your own body. (38-year-old, Malay, woman)

4.3.3 | Application of knowledge on asthma and self-management practices

Established self-management practices were a mixture of medical narratives and social practices. Mixed use of prescribed medication from the health services and complementary and alternative medicine (CAM) was discussed in most interviews, particularly among
people with uncontrolled asthma. CAM therapies and home remedies were widely used to counter symptoms. When participants reported beginning to feel any discomfort before the actual chest tightness or breathing difficulties, the inhaler was often applied to the chest and throat. A participant described the use of inhaler at the first sign of symptoms (Figure 21), mirroring what her mother used during the early stages of her acute asthma exacerbation.

But my mom uses Vicks. So, since I was a kid, I do practice rubbing Vicks on the chest, like my mom used to do. That thing actually helps. Really, it really helps with the asthma, especially when you just about to feel it, the tightness. (31-year-old woman)

All but one of the participants brought at least one photograph of CAM that they used for asthma. Despite this, CAM use was rarely discussed in consultations, as they expected that the healthcare professionals would not be open to the idea. Close friends and family members were reported as actively recommending some of these therapies. For instance, one participant photographed the traditional herbal medications introduced by her neighbour (Figure 21).

The dried crocodile meat, they cut into slices. My neighbour, she told me to boil it and drink, and your wheezing will disappear. I tried. Ah, I bought it. OK. I feel OK. It is just that I don’t tell my doctor about this, you see. I don’t think he will agree or he will believe this medicine. But I have to try, for my own sake. (54-year-old, Indian, woman)

Some who subscribed to the concept of Yin and Yang used warm water to counter asthma attacks. The hot and cold concept is widely understood in the Chinese culture, but it is also a concept accepted in Ayurvedic medicine in the Indian community. An Indian participant described and practised Ayurvedic medicine recommended by her mother-in-law to avoid being labelled as ‘sick’.

My mother-in-law practised Ayurvedic medicine. Ayurveda herbs and spices like black pepper are hot. She said, it’s perfect for asthma. If it’s hot, it can reduce the asthma attack. I always have the attack at night because it’s cold. I’ll straight chewed on the black pepper. Let it control my breathing, if that doesn’t work then only, I’ll take my inhaler. I don’t need to go to the hospital that often anymore. Before this, she [mother-in-law] always asked why I’m always sick, not like other people (sighed). (37-year-old, Indian, woman)

Stigmatising experiences were challenging and inevitably influenced self-management decisions. Sports and physical activities such as playing football were identified as essential activities in embodying health identities, particularly among two young men in this study. Thus, for these participants, using an inhaler before a game or during a match demonstrated ‘weakness’ and invited unwanted social reactions. One participant shared a photograph of a football field where he used to play and said (Figure 21):

When I feel like, I’m about to be breathless, and my breathing starts to be fast, I’ll continue playing. Other people can’t see it, and I don’t want to ruin my reputation. Or else, no one wants me in their team if they know I’m sick. I’m a better football player than anyone on that field! Besides, anyone who is running, their breathing will be fast. So, it’s normal. There’s no big deal about it, and my breathing will be back to normal by the end of the game. (28-year-old, Malay, man)

In contrast, formal social support helped some participants adopt a strong sense of identity and a positive attitude towards guideline-recommended care. One participant who joined a patient support group to improve physical health described how the weekly gathering had helped him embrace his identity and enabled him to empower others (Figure 21).

I took this photo during one of our weekly gatherings. Usually, we started with a session by the doctor or the pharmacist. They gave talks about health, including asthma, that’s where I know everything about how to take care of health. So, when other members of the club who don’t have asthma listen to the talk about asthma, they know a little bit about it. The highlight of the day will be snack time! The club members will take the turn to organise this. Sometimes they get together and cook at their house, so we will enjoy some home-cooked meal. It is during the mealtime that we chatted, we shared stories—good and bad. We feel belonged to something, and we are not ashamed of who we are: a person with asthma or diabetes or whatever it is. So, as a person with asthma, I actively find new asthma patients to join this club. Not just for them to know better about their illness but, to be among the people who understand what it is like to live with breathlessness. (56-year-old, Malay, man)

5 DISCUSSION

5.1 Summary of findings

Participants used formal and informal sources to access information about asthma and self-management. Struggles with language (both jargon and lack of translations) affected the understanding of
written information, while good communication with a healthcare professional could help overcome this. Most participants did not explicitly describe strategies to evaluate or check the health information that they received. Participants in this study used experiential knowledge to help evaluate the information they received about asthma. Understanding asthma and self-management practices were dominantly socio-cultural norms or practices. Sense of identity was influenced by stigmatizing experiences and social support, which affected their decisions and self-management choices.

5.2 | Interpretation of results and comparison with the literature

5.2.1 | Communication and understanding how people process health information

In this study, people with limited health literacy relied heavily on others for information about their asthma and how to care for it, reflecting the findings of Edwards et al., who concluded that people draw upon others’ health literacy skills in search of health information. Our participants regarded healthcare professionals as legitimate sources of health information, as has been reported in other studies. Although healthcare professionals are aware of this responsibility, they may selectively provide health information to patients, that is those with poor disease control or those whom they perceive may understand the health information. Some patients may even wish to discuss CAM with their healthcare professionals but fear negative reactions. The healthcare professional’s barriers to discussing CAM with patients include lack of a trusting relationship, personal disapproval of CAM and lack of evidence making a conversation about CAM uncomfortable.

Our participants wanted to understand asthma and manage it but described challenges in their communications with the healthcare professionals. People with limited health literacy may not necessarily tackle communication barriers and may not use strategies such as establishing rapport and clarifying queries. How health information is communicated (e.g., using universal health literacy precautions in providing health information) is not only important to help patients understand their disease but is also crucial in dismantling paternalism in doctor–patient relationships. Universal health literacy precautions include breaking down information and instructions into small steps, assessing comprehension through teach-back cycle and use of visual aids. Information tailored to the patient’s health literacy needs is more likely to be translated into positive health behaviour.

Knowledge and illness experiences from family, close friends and stories shared via social media were trusted informal sources of information among participants in this study. It has been shown that people look to the Internet (especially social media) to find others with similar illness experiences and use these stories to learn new strategies or confirm that their health behaviour is appropriate. The danger is that these experiences may not reflect accurate health information or recommended behaviours. A recent review that highlighted social media as a powerful channel for health communications similarly cautioned about unreliable content, lack of privacy of personal information. Others have suggested that superusers (users who write a large number of posts in online health communities) have the potential to reach a wide population and cost-effectively support such communities by providing accurate information about asthma and awareness about guidelines-recommended practice.

The lack of analytical skills to evaluate health information described by our participants could exacerbate the spread of false information and fearmongering against, for example, the use of preventer inhalers. Illness perceptions and personal health beliefs are grounded within social-cultural norms and practices. Nonadherence, for example, has been linked to mismatches between patients’ common-sense interpretations of their long-term illness and treatment and medical reasoning. Acknowledging patient’s views and empowering people with limited health literacy to understand their health and management has shown promising results. This has particular resonance in the context of our study where limited social health literacy was observed.

5.2.2 | Social elements, identity and limited health literacy: The impact on asthma self-management

Limited health literacy is not merely an individual trait; it is influenced by the characteristics of society and is a marker of multiple life circumstances and sociocultural challenges. It tends to affect vulnerable populations disproportionately, including people with lower educational attainment, people from ethnic minorities and those whose spoken language differs from the majority population. For example, our participants highlighted that health information in Malay was printed in Malay and English languages despite many people in this multilingual society speaking other languages, such as Mandarin and Tamil. This systematically hinders access to health information for some communities.

We found that language played a vital role in (inhibiting) knowledge exchange between the patients and their sources. Despite being a multilingual nation, interpreter services in Malaysian healthcare are scarce, echoing challenges reported in other healthcare services. Typically, services depend on healthcare professionals to recognize and address the language problems commonly by using family members as translators. Internet-based translations may not reflect the nuanced ethnic descriptions of illness. Resonating with our findings, ethnic differences in describing common asthma symptoms in multilingual settings may affect doctor–patient communication, delaying diagnosis and timely care.

Adjusting to life with asthma can be challenging, and the participants with limited health literacy in our study used various strategies to negotiate how to live with asthma despite difficulties with
understanding essential health information. Healthcare professionals may not be aware of these struggles and may lack the skills to address the patient’s life issues and sociocultural challenges in disease management.\textsuperscript{41} Stigma directly impacted the lived experiences and decisions made by our participants. Goffman (1963) defines stigma as an attribute that is deeply discrediting and reduced the bearer from a whole person to a tainted, discounted one.\textsuperscript{42} In many societies, to be healthy is the norm to which ill-health ought to be restored.\textsuperscript{43} Those with chronic illness (exemplified amongst our participants by the footballer and the daughter-in-law with asthma) struggled to meet this societal expectation and were assigned a sick identity, potentially affecting mental health.\textsuperscript{44} Our findings highlight the importance of not only focusing on the individual with asthma but on the broader social norms that provide the context to effective asthma self-management. More recently, social movements championing health issues (such as Asthma Right Care Initiatives\textsuperscript{45}) have significantly influenced health systems and are a force for societal change.\textsuperscript{46}

5.2.3 | The role of adaptations in cross-cultural research

In classic Photovoice methodology, the target community’s voice-making was conducted collectively.\textsuperscript{47} As participatory action research, it is bound to flexibility in terms of its conduct,\textsuperscript{48} particularly in overcoming sociocultural challenges (e.g., working with indigenous populations\textsuperscript{49}). Adaptations include the use of individual interviews and community events at which participants’ photographs were displayed on posters.\textsuperscript{50}

We recognized the importance of promoting community voice, which is central to Photovoice. The photographs from this study have been used within the community, although not in a traditional local photo exhibition. In an age of global collaboration and the Internet, our definition of ‘community’ is not constrained by geography. Our ‘exhibition’ reached beyond the local community to influence national stakeholders in Malaysia (at a stakeholder meeting attended by one of the participants) and via publications and websites (https://www.ed.ac.uk/user/respi/research/news/2021/world-asthma-day-photovoice-experiences-malaysia) to represent the global community of people living with asthma and limited health literacy. Although a 21st century adaptation of the Photovoice concept, it is our observation that this process has given ‘voice’ to this global community—and one we hope will increase as a number of colleagues in the NIHR Global Health Research Unit on Respiratory Health (RESPiRE) collaboration are planning similar Photovoice projects.

5.2.4 | Strengths and limitations

The Photovoice approach is conceived as participant-led research, giving voice to people to communicate their experiences in their own way. We adapted this to a more researcher-led approach, which has implications for the power balance between researcher and participants. For example, the researchers are clinicians, introducing a hierarchical power imbalance,\textsuperscript{51} which might deter coconstructions of knowledge with the participants and hinder understanding illness experiences in research interviews. We, therefore, put in place strategies to minimize the impacts on our research findings. Firstly, we used strategies described by Lincoln and Guba (see Table 1) to ensure the patients’ voices are represented in the findings,\textsuperscript{52} which might mitigate constructions of knowledge with the participants and hinder understanding illness experiences in research interviews. We, therefore, put in place strategies to minimize the impacts on our research findings. Firstly, we used strategies described by Lincoln and Guba (see Table 1) to ensure the patients’ voices are represented in the findings.\textsuperscript{53} During interviews, we observed that photographs helped shift the power balance to the patient’s experience as participants were reassured that the visualization helped clarify the experiences they were describing. We remained aware of the ethical and methodological strategies of Normal-Miller et al.,\textsuperscript{54} for example, checking the accuracy of photograph captions and preliminary themes with the participants. Participant involvement is a relatively new concept in Malaysia that limited early-stage involvement. Future studies could enable involvement with study conceptualization and design, further narrowing power differentials between researchers and participants.

The participants were recruited from multiple sites, purposively sampled to represent the varied sociodemographic backgrounds of the Malaysian population. Participation in Photovoice activities was offered to all participants with no selection by the researcher, though the topics covered in the interview may have influenced decisions to participate. We used robust approaches to ensure trustworthiness. We provided a participant video to supplement written information and help improve understanding of the research. Infographics explained the conduct of Photovoice and encouraged creativity in completing photo-taking tasks.

The initial in-depth interviews were representative of the intended range of demographic characteristics and asthma control, though only a minority of participants took part in the Photovoice phase, in part because of the time and commitment needed to complete this. As a result, we lacked older participants and those of Chinese ethnicity among those who completed the Photovoice interviews. In classic Photovoice methodology, we would only have recruited participants willing to commit to the photo-taking. Our adapted approach with initial qualitative interviews meant we heard from a broader range of people enabling us to embed Photovoice insights in the broader context.

The use of a predetermined framework ensured a structured approach to developing our topic guides and informed our analysis. We remained aware, however, that this could restrict our data collection and interpretation of novel themes. We, therefore, explicitly looked for discordant views and unexpected themes. The Photovoice interviews enabled the participants to determine the topics for discussion, and because these progressed in parallel with the interviews, we could accommodate novel insights into the
FIGURE 3 Change mechanisms that may be applied for interventions at different levels to improve understanding of asthma and self-management practices.

ongoing interviews. The presence (or lack) of photographs triggered discussion of issues important to the participants enabling them to set the agenda. Language barriers were overcome as participants used photographs to express their experiences, and the interviewer prompted discussion about persons, objects, or settings depicted in the photographs. Conversations about photographs they were unable to capture, triggered reflection on important—but hidden—concerns like mental health. The interactive and photos provided a data source triangulation that enhanced understanding of health literacy experiences in real life and challenged us to think beyond the health system to how health literacy operates at the societal level. Interviews were conducted in the participant’s spoken language to capture the cultural nuances, and we preserved this during the translation process.

5.3 | Implications for policy, practice and research

Targeted asthma care for patients’ health literacy needs has a pivotal role in improving understanding of asthma and guideline-recommended self-management practices. Multilevel interventions (interpersonal, health system, community and policy) may be needed to achieve this. Based on our findings, we propose a framework for considering changes that might tackle health literacy issues in asthma care (Figure 3) and which potentially, may be adapted to other chronic conditions. Future research is needed to determine the feasibility and effectiveness of such multilevel interventions in low-middle-income countries (LMICs) settings.

6 | CONCLUSIONS

Health literacy and asthma self-management remain a challenge in many healthcare settings, with particular challenges in multilevel LIMICs. We have described the experience of people with asthma in Malaysia based on an established health literacy framework. The photographs stimulated a unique insight into the challenges people with limited health literacy face in living with asthma and how they navigate the health system to care for their health. Multilevel, locally developed solutions that tailor health services, enable appropriate trusted information to support self-management, and raising societal awareness about living with asthma may help people accept and adapt to the diagnosis, lessen stigma and cope with the demands of living with asthma.

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The RESPRIE collaboration comprises the UK Grant holders, Partners and research teams as listed on the RESPRIE website (https://www.rspriepi.uk/respirie), including Aziz Sheikh and Harish Nair.

The photographs included in this article were taken by participants of this study who had permitted the photographs to be used in any format within academic reports, publications and presentations of noncommercial nature.

CONFLICT OF INTERESTS
The authors declare that there are no conflict of interests.

AUTHOR CONTRIBUTIONS
Hani Salim, Ingrid Young, Ping Yin Lee, Sadilla Shariff-Ghazali and Hilary Pinnock had full access to all the data and were involved in the interpretation of the data. Hani Salim wrote the initial draft of the paper with Hilary Pinnock to which all the authors contributed. Aziz Sheikh was Director of RESPRIE, led the securing and distribution of research funds and contributed to the development of the research protocol and overseeing the monitoring of its progress. Harish Nair commented critically on a draft of the manuscript. All authors approved the final draft.

DATA AVAILABILITY STATEMENT
The datasets (texts) analysed during the current study are available in the Edinburgh DataShare repository, https://doi.org/10.5488/eb/2753. The photographs that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ORCID
Hani Salim http://orcid.org/0000-0002-7471-8678
Ingrid Young http://orcid.org/0000-0002-1242-5992
Ping Yin Lee http://orcid.org/0000-0002-0912-6643
Sadilla Shariff-Ghazali http://orcid.org/0000-0002-5737-7226
Hilary Pinnock http://orcid.org/0000-0002-5975-8386

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SUPPORTING INFORMATION
Additional Supporting Information may be found online in the supporting information tab for this article.

Appendix 15 The adapted Photovoice interview guide [179]

<table>
<thead>
<tr>
<th>Topic</th>
<th>Question</th>
<th>Prompts (when applicable)</th>
</tr>
</thead>
</table>
| **Asthma experience**        | 1. Tell me about your experience as a person with asthma?                | • The feeling of having asthma (stigmatization)  
• Understanding of asthma and its control.  
• Dealing with daily symptoms.  
• How long do you think your asthma will last? |
• How you describe your condition to others?  
• Does what other opinion matter to you? |
|                              | 3. How does life affect your asthma?                                     |                                                                                             |
|                              | 4. Where do you find out about asthma?                                   | • What do you have found out so far?  
• Source of information: Clinic? Family? Friends? Internet? |
| **Asthma management & control** | 1. Is your asthma well-controlled or troublesome?                         | • Why do you say so?  
• Why do these happen?  
• Who will get poor asthma control?  
• Do you think you are at risk of poor asthma control?  
• Can you give me an example of a time when you did not have good control of your asthma? What happened? What lead up to this? |
|                              | 2. Can you tell me more about how your asthma being managed? (Clinic or other alternatives) | • How do you think it should be managed?  
• If Alternative care: can you share more about it and why do you think you preferred this mode of care?  
• If hospital care: can you share how you being cared for by the healthcare system? Why do you think you preferred this mode of care? |
|                              | 3. What is your opinion about the medical service provided to care for asthma? | • Healthcare personnel: Communication?  
• Facilities: accessibility? Cost?  
• Is routine care important? Why would some go for routine follow up? Would you engage in routine care & why?  
• How can it be improved?  
• Do you think inhalers works? Why is that so? |
| **Asthma self-management & support** | 1. Asthma isn’t always about doctors and clinics but about what you do every day. | • Can you tell me if you do anything in particular to help with your asthma? |
|                              | 2. Have you heard about the asthma action plan? (Provide sample)           | Participant knows about AAP  
• Who educate you about it and what was discussed?  
• How often are you reminded about using it?  
• How can this teaching session be improved?  
• Any benefit and problem using AAP?  
• If no, do you think there is a need to teach you on asthma action plan/self-managing asthma at home?  
• How can the doctor help you to do this?  
• Any other methods to facilitate you to use AAP in the future? |
|                              | 3. What would help you to manage your own asthma?                         | • What format that you prefer? Example: Paper-based/Website/mobile apps/social media |
| **Closing**                  | 4. As a person with asthma, what are your hopes for the future?           |                                                                                             |
Appendix 16 Infographic guidelines on photo-taking activity

Do's & Don'ts

Take photographs of anything that you feel is linked to your experience living with asthma and care for it.

Don't worry about taking the perfect photograph.

Be as creative as you like.

Don't take close-up photographs of people (adult or children), especially if you have not asked them for their permission - please remember to respect people's privacy.

Do ask people if it is OK to take their photograph before doing so. They need to sign consent for this.

Don't put yourself at risk of harm or danger when taking photographs (e.g. do not take a photograph when crossing the road).
## Appendix 17 Examples of the translation process

<table>
<thead>
<tr>
<th>Original language (Type)</th>
<th>Sample quotations</th>
<th>Translation to English</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mandarin</td>
<td>那個他沒有教。他只是教如何使用吸入器而已。他有分咐只要吸入器變空時就可以來換。</td>
<td>This one they didn’t teach. They just taught me how to use the pump, nothing else. They say, when this (the inhaler) is empty, to come and exchange. Sometimes, after three months, it’s (the inhaler) is empty, I change. Sometimes, when I use it frequently, I need to come to exchange after a month.</td>
</tr>
<tr>
<td>Mandarin</td>
<td>啊，在工厂做工時已經有患上這個病了。開始做工的時候是沒有毛病。偶而去看醫生也是因為肺部不舒服。過了一段時間，醫生診斷出來有可能會是得了哮喘病。</td>
<td>I got it (asthma) when I worked at the factory. When I first started, I didn’t have this (asthma). Then, I saw the doctor because my chest didn’t feel right; eventually, the doctor said I might have asthma. After that, he didn’t give any pump (inhaler), only the tablet. He said this (the tablet) is more for temporary usage. After a while, after a year, I took this tablet, but not very frequent. [After that], I didn’t see the doctor anymore. I just bought the tablet. I took it when my chest felt tight; then I took it. Then, one time, my friend told me, ‘You go and check. The pump (the inhaler) is better’. After that, I came to the health clinic.</td>
</tr>
<tr>
<td>Malay</td>
<td>Bila saya dapat tahu dia main barang (dadah), saya angin. Sebab masa saya kahwin dengan dia ada bawak anak tiri 5 orang. Dia bawak semua anak dia dari X datang duduk dengan saya. Saya banyak kisah saya ni, banyak. Salah seorang dariapada anak tiri saya, saya dah dera, memang sebat betul. Saya dah masuk dalam sebab tu, penjara Y 23 hari. Haa, saya masa tu tengah mengandung 6 bulan. Nasib lah saya tak beranak dalam oenjara. Hmm (terdiam lama). Stress dengan susah nafas selalu. Anak dia semuanya degil. Suami tak peduli saya.</td>
<td>When I found out he was taking stuff (drugs), I was upset. Because when we married, he brought along his 5 children. He brought all his children from X to live with me. I have many stories, a lot. One of my stepsons, I abused him, I caned him. I was jailed because of that, in Y Prison for 23 days. Haa [colloquial term used to emphasise an opinion or statement], I was 6-month pregnant at the time. It was fortunate that I didn’t give birth in prison. Hmm (long paused). I was stressed and feeling breathless all the time. His children were stubborn. My husband didn’t care about me (sighed).</td>
</tr>
<tr>
<td>Malay</td>
<td>Bila doktor terangkan, saya dengar lah apa dia cakap pasal asma dengan ubat sekali, sebab dia pakar. Kalau saya tak dengar, saya tertinggal lah nak tahu benda yang saya tak tahu atau tak pasti. Saya dengar la baik-baik apa dia (doktor) cakap sebab saya mana tahu nak belaia benda-benda ni dari mana. Saya takut la juga kalau buat sendiri, saya baca benda salah. Jadi tu yang macam selalu bergantung pada apa yang dia bagitahu.</td>
<td>When the doctor explains, I listen to what he explains about asthma and the medications because he’s the expert. If I don’t listen, I’ll miss the things that I don’t know or I’m not sure of. I have to listen carefully [to the doctor] because I don’t know where else to learn about these. I’m afraid, on my own, I may read the wrong information. So, I only depend on what the doctor told me.</td>
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<tr>
<td>Malay</td>
<td>Tamil</td>
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<td>Kalau macam banyak gamba sikit bagus. You tahu, macam anime, apa itu langkah-langkah jadi macam cerita, jadi senang mahu faham. Tapi ini kertas hitam putih. Tak menarik. [...] Tu App telefon, bagus juga, I boleh kasi check apa masa. [...] Atau macam kasi tunjuk video guna inhaler. I jarang need [to] use inhaler I tapi kalau mahu guna, kadang-kadang macam lupa.</td>
<td>That day I [went] to take medication at a government clinic, and [I'm] planning to continue my follow-up there. I informed them that I am an asthma patient. After an examination, the doctor told me [that] I do not have any symptoms, so he can't give the [asthma] medication. But he said I should come there when I have an [asthma] attack, then I will be given the medication.</td>
<td></td>
</tr>
</tbody>
</table>

But a bit more images is good. You know, like anime, so the steps will be like a story and easy to understand. But this paper is also black and white. Not interesting. [...] The mobile app, that's useful too, [as I] can refer to anytime. [...] Maybe we can put a video on how to use the inhaler. I seldom need [to] use my inhaler, but when I need to, I forget.
Appendix 18 Examples of exploring narrative types

<table>
<thead>
<tr>
<th>Participant</th>
<th>Interview 7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interview phase</td>
<td>Initial interview</td>
</tr>
<tr>
<td>Age, gender, ethnicity</td>
<td></td>
</tr>
</tbody>
</table>
| Medications          | Metered-dose Inhaler (MDI) Salbutamol  
                      | Metered-dose Inhaler (MDI) Budesonide |
| ACQ: 4.5             | Uncontrolled |
| Health literacy score | 6           |

Summary of life story with asthma:
Currently, he described that his condition was terrible, and he felt breathless every day of his life. He reported attending the emergency care almost every night for breathlessness. Despite daily preventer and oral steroids, his symptoms did not recede. He admitted owning a nebulisation device at home, mimicking the emergency care, to be used if he was too breathless to ride to the nearby health facilities or had an attack at night. He recalled being admitted to the hospital once, in early 2000, where he was intubated after he collapsed at home.

In the last 6-month, he noticed that his symptoms progressively worsened, and the treatment, both medical or alternative/homemade therapies, did not seem to work. He described feeling easily tired and became breathless even walking a short distance on level ground.

**Living with asthma**

P7 was first diagnosed with asthma at the age of 10. His late mother told him that he had wheezing episodes at the time requiring multiple hospital visits. Although he was prescribed medications (inhalers), he was not getting any better. His family then tries multiple complementary and alternative medications (CAM) but to no avail. He still struggled to find the therapy that could help with his breathing and spent much money for this purpose. Finally, he opted for CAM if being recommended by friends or someone close who has asthma. He expressed the feeling of anxiety about what might trigger his attack as his attack could be unpredictable. He recalled a strong family history of asthma from his paternal side and his siblings.

P7 described stigmatising experiences at work where he was frequently ostracised at work colleagues due to frequent breathlessness requiring him to be off work because he was sick. Many times, he required emergency care for severe asthma exacerbations. The superiors and workplace environment were not very supportive of his condition, according to P7. The frequent symptoms were debilitating and affected his life. The thought of death always lingered, especially during an attack. He described that he did not only experience difficulty in breathing but also physical pain associated with the breathlessness. He wished to die and be done with it after each severe asthma exacerbation than to experience this episode again. He kept his problems and anxiety to himself, fearing being labelled as 'whiny' or 'sickly' even with close family members, relatives, and friends. He felt that he was a burden to the family. He implicitly admitted taking alcohol to be free of worldly problems, particularly his health.

He was diagnosed with diabetes and hypertension in his early 40s. He had multiple medications and admitted that adherence was poor, resulting in poor control of Type 2 Diabetes and hypertension.

P7 completed primary education and had basic reading and numeracy skills. He previously was a coal miner and, at present, worked for a palm oil factory. He is married and has a son. He described being the sole breadwinner of the family and faced financial difficulties with making ends meet. He lived in a deprived area, and despite financial difficulties, he owned a nebuliser machine, partly due to safety when travelling at night. He recalled being mugged after receiving care at the emergency unit at night, where he suffered minor injuries but was traumatised to go out at night to get medical care.

**Understanding of asthma, self-management and adherence to prescribed therapies.**

P7 had a trust issue with the health system in general due to his experience related to the previous management of his mother's illness; he still blamed her death due to the perceived failure of the doctors to diagnose her condition in time, despite seeking early medical attention. P7 perceived that doctor did not have patient's interests in mind and did not take responsibility for their mistakes.
He attributed asthma to a genetic condition, although he did not understand why his son does not have asthma. He learnt about asthma and how to care for it from his mother and the village monk. Although he recalled his doctor's patient education sessions, he could only remember what his mother and the monk told him, especially on what to do during an attack. If he started to feel discomfort at home, he would ask his wife to apply ointment and massage his back. If this failed, he would use his nebuliser machine at home. He had been prescribed an asthma action plan in the past, but he described having been taught about it once, which he had difficulty understanding. He never used or seen it ever since. As for the inhalers, he described using it only outside the home as it was small and easy to carry. He perceived that oral steroid as a 'wonder drug', based on his experiences. According to P7, oral steroids and salbutamol solutions for the nebuliser machine were available over the counter at various pharmacies and private primary care clinics.

Outlook on life:

P7 described having no hope of any sort. Sorrowfulness dominates his thoughts, and he felt powerless about what he can do in life. Life is like a dead-end to him, and the thoughts of death were frequent.

<table>
<thead>
<tr>
<th>Plot structure</th>
<th>Hopelessness, powerless</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of narrative</td>
<td>Chaos</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Participant</th>
<th>Interview 18</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interview phase</td>
<td>Initial and photovoice interviews</td>
</tr>
<tr>
<td>Age, ethnicity, gender</td>
<td>37, Indian, woman</td>
</tr>
<tr>
<td>Medications</td>
<td>Metered-dose Inhaler (MDI) Salbutamol, Metered-dose Inhaler (MDI) Budesonide</td>
</tr>
<tr>
<td>ACQ: 1.5</td>
<td>Uncontrolled</td>
</tr>
<tr>
<td>Health literacy score</td>
<td>22</td>
</tr>
</tbody>
</table>

Summary of life story with asthma:
P18 has insight that her asthma is not controlled as she recalled experiencing frequent asthma exacerbations of late but described that her asthma was in good control overall. She recalled an incident the night before the interview terrified her, and she feared she would die. She drank a glass of warm water and sat down, hoping that the shortness of breath would go away. While praying to God that she would die, she distracted herself with a photo of her niece and her children. When this action did not work, P18 took her inhaler and the symptoms slowly improved. She experienced pain and shortness of breath, but she could not pinpoint the source.

**Living with asthma**

P18 was first diagnosed with asthma at the age of 8-year-old. She recalled having a fit episode after her mother applied a traditional bamboo ointment brought from India. P18 was hospitalised for two weeks for other issues, including a breathing problem. She was discharged home with an asthma diagnosis, but no inhaler was prescribed. Instead, she recalled visiting the health centre for nebulisation if she had any attack. From thereon, P18 recounted multiple asthma exacerbations episodes requiring nebulisation at the emergency unit. As a child, she remembered the chaos of attending the health centres in the middle of the night. The frequency of breathlessness affected her schooling experience. She recalled not engaging in many school activities, being side-lined by school administrators due to fear of an asthma attack, and being frequently away from school. Her parents, particularly her mother, was not very supportive of her being active at school. She remembered her mother telling the school not to let her participate to avoid asthma exacerbation. Being asked not to participate in school activities angered P18, mainly because she blamed her mother for causing her asthma. P18 believed that the traditional ointment given by her mother when she was small caused the initial asthma episode. She was devastated that she could not take part in school activities and felt different from her peers. She suffered from verbal abuse from peers and was labelled as ‘sickly’. She recalled not being allowed to eat a long list of food and beverages, which might trigger asthma exacerbations. Thus, when eating out with the family, she could not order the food her siblings could order. The different treatment she received set her out from her siblings who did not have asthma. P18 recalled hating herself all the time for not being treated fairly.

However, her symptoms improved when she started secondary school (13-year-old). The symptoms stopped until she was about 16. After that, both P18 and her mother thought that P18 was cured of asthma. However, P18 recalled that her school leaving the blank certificate column for any extra-curricular activities and feared that she would never get a chance for further education or a job with the blank columns. Then, one day a teacher, gave her a chance to play table tennis, which changed her life. P18 knew nothing about table tennis, but she was determined to prove herself, which she did. Winning the school tournament boosted her confidence, and the responsible teacher never stopped motivating her.

After school, she initially worked at a small electrical appliance’s assembly factory, but this did not last long as she had trouble with the dust and stuffy environment. In addition, her asthma exacerbations were frequent, requiring emergency care and prompting her to quit the job. At this point, P18 was being prescribed an inhaler. According to P18, the inhaler gave her a sense of security that anytime she experienced an asthma exacerbation, the inhaler would prevent her condition from worsening.

P18 was married in her early 20s and had her first child at the age of 21, where her breathing problems worsened. Her symptoms include night coughs and difficulty in breathing, and at the time around, she was not sure of the trigger. However, she recalled that her condition took a turn for the worst, and she required multiple hospitalisations throughout her pregnancies. She described these experiences as frustrating. At this point, P18 inhaler therapies were stepped up to include an inhaled steroid. In addition, she underwent a Caesarean section for both of her children. On both occasions, P18 remembered the experience of ongoing pre-and post-delivery symptoms, where several exacerbations required hospitalisation.
Her first son had multiple viral bronchiolitis infections requiring admissions since birth. However, P18 always blamed herself for her son's condition because of her ongoing uncontrolled asthma during the pregnancy. To make for this guilt, P18 described working hard to ensure that her children received the best education she could provide, such as spending money for extra classes after school hours. In addition, P18 took life insurance to secure her children financial needs should she pass on before her time. As a mother of two children, caring for the active growing up boys posed a significant challenge to P18. She barely had the energy to cope with their needs and wants, particularly when she was unwell and needed the rest. Although she had help from her mother-in-law, who lived nearby, the demand of caring for small children, coping with her own illness and her role as a working mom was overwhelming. She felt tired all the time and had to limit her activities with her children for fear of attacks, e.g., swimming or exercising outdoors. Now that the boys are in their teens, P18 described them as more understanding and could take care of themselves when she was unwell. However, the boys did ask about her well-being and why she needed the inhaler. P18 took the time to explain to her children and avoided explaining too much for fear of worrying them. Sometimes, P18 recalled, when she needed to use the inhaler, they were the ones who made sure her inhaler was available to be used.

P18’s relationship with her husband was affected by her asthma. She described having to drink warm water before any intimate encounter. According to P18, her husband was supportive and understood her health condition. On further discussion, P18 described not discussing her poor asthma control and other health problems with her husband after being told she ‘Whines’ a lot. She perceived this was a way for her not to burdened her husband, who also had other health issues.

However, her husband was a heavy smoker, an image she wanted to capture on film but could not. He smoked indoor, although he knew P18 had asthma in the presence of the children, in a car; for example, he would avoid smoking, which made P18 felt less important in her husband's eyes. She described feeling angry about this but kept it to herself, as verbalising her anger might paint a negative picture of her as a wife to the surrounding people. He had tried to quit smoking owing to health concerns and smoked only one box each day out of five, for which P18 decided she should not complain anymore.

P18 enjoyed the company of her sister's family, who lives nearby, particularly her niece, whom she took photographs. She commended that being around children makes her happy, including immersing herself by playing with the children at the playground (a photograph) or recreational park. She described these as ways to release her stress. P18 remarked about a lesson her grandfather told her about talking to nature about her issues when she was lonely and had no one to talk to. This lesson occurred when she rushed to him one day after a bullying episode at school. She shared photographs of trees near her house, where she sat and let her heart out. P18 learned about the medicinal values of plants from her grandfather as well. Her car was also considered her best buddy because it constantly 'witnessed' her at her lowest point. She sat in the car when she was sick, unhappy, or needed to escape life's difficulties. P18 viewed living souls as less trustworthy and sensitive towards others, a perception she developed over time based on her encounters with others.

P18 had no other social network apart from her colleagues at work. Over time, her family's commitment made her lose contact with other friends. P18 often went to the movie alone, choosing feel-good movies that could lift her spirit. She watched motivational videos on YouTube, watching cartoons she enjoyed watching as a child and devoted herself to prayers for the same reason. Using a photograph of Buddha statues, P18 highlighted her coping strategy for dealing with life's difficulties or finding 'peace.' She recognised that she would not be able to cure asthma, but she might be able to control it.
At present, P18 works at a recording unit where she deals with files and record's storage. Her main challenge with this job was that her constant exposure to dust within a confined environment. She applied a strategy such as using masks but later realised that she was allergic to the mask surface, thus needing a cloth-based mask. Her colleagues at work are supportive of her condition. If she needs treatment at work, she will be covered by other colleagues. At night she took a part-time job for financial security for the family. The long working hours sometimes took their toll on her health. However, according to P18, she was inspired to work hard by her mother, a single parent who worked various jobs to support four children and put three of them through college.

Understanding of asthma, self-management and adherence to prescribed therapies.

Adherence wise, P18 diligently took her daily preventer. Due to the unpredictability of her asthma exacerbations, she always had a spare of her 'blue' inhaler at several places, e.g., car and handbags. She also described taking both her preventer and rescue inhalers during exacerbations. Based on her experience, P18 described that using both inhalers reduced the severity of the attack and avoided the need for nebulisation. P18 was also not keen to received nebulisation for fear of being admitted and worried about childcare issues. She also opened up to taking a course of oral steroids if the symptoms did not go away completely, roughly 1 to 2 tablets taken about 2 to 3 times a month. Her last oral steroid therapy was during an exacerbation two months before the interview.

Using photographs, P18 described the way she managed her asthma symptoms at home. She had a strong belief in Ayurvedic therapy. P18 described drinking warm water and rest in her car before she could work again. She believed the warm water would create a warm environment that prevented another attack. Hot-based home remedies are good for preventing or stopping exacerbations, such as black pepper or ginger, which P18 had been using as first-line therapy. Other home remedies include honey which was perceived to be good for cough. If this did not work, P18 would use the inhaler, and if failed, she would then rush herself to get to the emergency unit. P18 learnt how to use home remedies and traditional practices from her husband's grandmother and mother-in-law, whom she respected. P18 also watched videos on YouTube, which she found in her search to make home remedies. She felt that these were essential knowledge. Besides, all the ingredients were easily found in her kitchen and can be easily made when needed.

Appointment wise, P18 did not have any fixed appointment mainly due to the demand of her work needing her to be constantly available at her workstation. However, P18 rearranged her follow up when her presence at her workstation was less needed. Apart from checking on her symptoms and performing a physical examination, she discussed using a peak flow metre and oxygen saturation during this session. She received education on inhaler techniques from the pharmacist, which strengthened her skills. However, she had never heard or seen an asthma action plan. When discussing paper-based health information about asthma or an asthma action plan, P18 reported that such a format was not practical in her daily life and might easily be misplaced.

Other medical issues for P18 include allergic rhinitis requiring medical therapies and a recent diagnosis of heart problems. Besides dust and cold food, P18 observed that car air-conditioning system, emotional distress and lack of sleep could cause asthma exacerbations.

Regarding her relationship with her doctors, P18 admitted they were kind and helpful, but due to the number of people they were seeing, there was a lack of meaningful communication between her and her doctor. She perceived that the relationship was superficial, only focusing on her asthma when she was not well.

Outlook on life:

Overall, P18 had no regrets about her health. She accepted to be a person with asthma. P18 accepted that there is no cure for asthma and that she needed to control her symptoms. However, P18 was hopeful that she would not be dependent to her inhaler and that her asthma is cured so she could live like anyone else. P18 believed that her faith in God will help her look at the positive aspect of life.
<table>
<thead>
<tr>
<th>Plot structure</th>
<th>Resigned but hopeful.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of narrative</td>
<td>Endurance</td>
</tr>
</tbody>
</table>
Appendix 19 Examples of exploring themes within participant’s story

**Theme 2: Re-claiming identity in network of everyday relationships**

<table>
<thead>
<tr>
<th>Sample quotations</th>
<th>Stage 1 interpretation</th>
<th>Stage 2 interpretation</th>
<th>Stage 3 interpretation</th>
<th>Sub-themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>I’m just a wife, nothing much I can say when it comes to his behaviour and not helping out with the household when I’m sick. So, I must be the one who manage everything especially caring for the children. I must respect him, if I want to call myself a good and considerate wife. Even our religion teaches us to be obedient.</td>
<td>The definition of a good wife is anchored to religious understanding.</td>
<td>I’m a considerate wife</td>
<td>Social identities based on gendered roles</td>
<td>Managing social expectations</td>
</tr>
<tr>
<td>Sometimes, I cannot stand the [asthma] problems – the cough, the breathing. It keeps coming. But I have to force myself to do work at home, tend to the children, [and] cook for the husband. My husband (sighed) once said, “you better just do your work at home, don’t complain too much. [You] keep saying you’re sick” he said. Then on, I just tried keep to self, my problems. I don’t want [to] burden my husband. I think he had enough problems to deal with at work. I want to be a considerate wife (doeful expression) At night, I actually will feel sad, I feel useless because I don’t know how to tell him about my asthma […] about asthma, basically. I want to tell him, make him understand that I can die because of asthma, but why? How? When? These I don’t know!’</td>
<td>Forcing self to accomplish tasks despite poor health to be a considerate wife.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I don’t know how to tell him that with this asthma and I’m tired even to breathe. What do I do? He wants to be together [sex], sometimes I too, but I may get breathless and needs the inhaler. So, before we do it (sex), I’ll drink warm water and rest for five minutes. […] You know, people say this asthma is a cold illness, so you counter-act with hot stuffs like warm water or ointment. Whichever option I can easily get.</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
### Theme 3: Defining interactions with the health system and environment.

<table>
<thead>
<tr>
<th>Sample quotations</th>
<th>Stage 1 interpretation</th>
<th>Stage 2 interpretation</th>
<th>Stage 3 interpretation</th>
<th>Sub-themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>My husband already smokes for a long time. I don't think he want to stop. we</td>
<td>Negotiations to discuss smoking cessation result in</td>
<td>Ongoing struggle with smoking partners at home.</td>
<td>Mediating indoor pollution</td>
<td>The environmental challenge of managing one's asthma.</td>
</tr>
<tr>
<td>have discussed before but then we fight. [...] So, I just advise him here and</td>
<td>arguments.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>there. I just can't ask him to stop what he likes to do.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ha’ah, already said many times lah. Cannot do anything. If understanding he</td>
<td>Numerous discussions about quitting smoking are</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>won’t smoke in the room.</td>
<td>pointless.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My husband smokes and it makes my asthma difficult to control. But it really</td>
<td>Feeling helpless in efforts to persuade partners to</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>breaks my heart to see him do that. I can't do anything to make him stop.</td>
<td>quit smoking.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

[Appendices] 424
# Appendix 20 Examples of the health literacy framework analysis

**Health literacy: negotiating medical narratives and social practice.**

<table>
<thead>
<tr>
<th>Sample quotations</th>
<th>Stage 1 interpretation</th>
<th>Stage 2 interpretation</th>
<th>Sub-themes</th>
<th>Domains of health literacy</th>
</tr>
</thead>
<tbody>
<tr>
<td>But my child has eczema, my first child, because the doctor say that he has the asthma. He does have eczema and we follow up at Hospital H. I know that eczema, asthma, allergy is all related.</td>
<td>Chronic illness which may be related to other inflammatory diseases</td>
<td>Understanding of asthma in-line with Health Literacy Framework</td>
<td>Understanding of asthma based on basic scientific understanding.</td>
<td>Understanding information on asthma and self-management</td>
</tr>
<tr>
<td>Yeah, my understanding is that, the airway blocked then after that, because of maybe certain allergies or anything, they get swollen. And when it swelled up then it (the airway) closed up, so the breathing becomes bad.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>My own family…my mum probably she takes the spray into the nose chit chit (as if spraying inside the nostril) …aa that. I don’t know about sinusitis sneezing in the morning but I heard the doctors said it’s related to asthma.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>When it stopped, I don’t remember? I just remember a little bit. I don’t really remember much. When I was a kid, the sound was loud. That one I remember. The sound was loud, but it didn’t feel that bad. We thought it was not that bad right, I didn’t go to treat it. Village people doesn’t really go for treatment right. Hospital was too far and we don’t have the money. Back then it was just traditional medicines, the herbs. Like garlic oil, when cough applied the garlic oil (massaging her chest). Village people didn’t really go to the clinic, the hospital. It stopped maybe around when I was seven or eight years. But the doctor said it is common to happen like this.</td>
<td>Illness may vary overtime and intensity and health state, e.g., pregnancy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My asthma came back, when I was pregnant. The doctors did warn me when I first get pregnant. They said my asthma can be worst. It came back hard; it was bad when I was pregnant. Bad. But I didn't go to the clinic. Going to the clinic just to check the pregnancy only. It became a problem to go frequently, because we are too far in the rural area. We didn’t have the transportation to go. My husband only had a bicycle.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
But usually when I get the flu (asthma exacerbation) will happen. If the flu is bad, a bad one. A bad flu is when the one whole day I’ll just be sneezing. From the morning I sneeze only. If the flu last for 2-3 days, I would get the asthma attack. So, the doctor said to just use the inhaler again. Always like this.

Some people said that if you got asthma you tend to get TB. When I cough so bad, I will be worried. The TB has come? I thought. Every time it goes away, I was happy. Meaning my asthma did not turn into TB.

Coughs is an infectious disease relating to tuberculosis (TB). Socio-cultural influence to understanding asthma and self-management. Health beliefs may shape understanding of asthma and perceptions of control.

Yeah, during that time, when I started the coughing. People said, “Got see doctor or not, see got TB you know?”. I believed this you see, for a very long time. How many times I went to the clinic for x-rays?
Appendix 21 Part of the Design Sprint’s findings were published in the Journal of Medical Internet Research

Developing an Asthma Self-management Intervention Through a Web-Based Design Workshop for People With Limited Health Literacy: User-Centered Design Approach

Hani Salim\textsuperscript{1,2}, MMed; Ping Yin Lee\textsuperscript{1}, MMed; Sazlina Sharif-Ghazali\textsuperscript{1,2}, PhD; Ai Theng Cheong\textsuperscript{1}, PhD; Jasmine Wong\textsuperscript{1}, MBBS; Ingrid Young\textsuperscript{2}, PhD; Hilary Pinnock\textsuperscript{1}, MD; RESPIRE Collaboration\textsuperscript{1}

\textsuperscript{1}NIHR Global Health Research Unit on Respiratory Health (RESPIRE), Usher Institute, The University of Edinburgh, Edinburgh, United Kingdom
\textsuperscript{2}Department of Family Medicine, Medical Faculty and Health Sciences, Universiti Putra Malaysia, Serdang, Malaysia
\textsuperscript{3}UM eHealth Unit, Faculty of Medicine, University Malaya, Petaling Jaya, Malaysia
\textsuperscript{4}Malaysian Research Institute on Ageing, Universiti Putra Malaysia, Serdang, Malaysia
\textsuperscript{5}Centre for Biomedicine, Self and Society, Usher Institute, University of Edinburgh, Edinburgh, United Kingdom

these authors contributed equally

Corresponding Author:
Hilary Pinnock, MD
NIHR Global Health Research Unit on Respiratory Health (RESPIRE)
Usher Institute
The University of Edinburgh
Old Medical School
Doorway 3, Teviot Place
Edinburgh, EH8 9AG
United Kingdom
Phone: 44 0131 650 94
Email: hilary.pinnock@ed.ac.uk

Abstract

Background: Technology, including mobile apps, has the potential to support self-management of long-term conditions and can be tailored to enhance adoption. We developed an app to support asthma self-management among people with limited health literacy in a web-based workshop (to ensure physical distancing during the COVID-19 pandemic).

Objective: The aim of this study is to develop and test a prototype asthma self-management mobile app tailored to the needs of people with limited health literacy through a web-based workshop.

Methods: We recruited participants from a primary care center in Malaysia. We adapted a design sprint methodology to a web-based workshop in five stages over 1 week. Patients with asthma and limited health literacy provided insights into real-life self-management issues in stage 1, which informed mobile app development in stages 2-4. We recruited additional patients to test the prototype in stage 5 using a qualitative research design. Participants gave feedback through a concurrent thinking-aloud process moderated by a researcher. Each interview lasted approximately 1 hour. Screen recordings of app browsing activities were performed. Interviews were audio-recorded and analyzed using a thematic approach to identify utility and usability issues.

Results: The stakeholder discussion identified four themes: individual, family, friends, and society and system levels. Five patients tested the prototype. Participants described 4 ways in which the app influenced or supported self-management utility: offering information, providing access to an asthma action plan, motivating control of asthma through support for medication adherence, and supporting behavior change through a reward system. Specific usability issues addressed navigation, comprehension, and layout.

Conclusions: This study proved that it was possible to adapt the design sprint workshop to a web-based format with the added advantage that it allowed the development and the testing process to be done efficiently through various programs. The resultant app incorporated advice from stakeholders, including sources for information about asthma, medication and appointment reminders, accessible asthma action plans, and sources for social support. The app is now ready to move to feasibility testing.

(J Med Internet Res 2021;23(9):e26434) doi: 10.2196/26434
KEYWORDS
asthma; self-management; design sprint; health literacy; mobile phone

Introduction

Background

Supported self-management for asthma (written action plans and regular review) is highly effective at improving control and reducing acute attacks [1-3]; however, globally, it is challenging to implement for 334 million people living with asthma [4-7]. One of the challenges is the need to tailor support for people with limited health literacy. Health literacy is defined as the degree to which individuals can obtain, process, and understand the necessary health information needed to make appropriate health decisions [8]. Studies have associated limited health literacy with erroneous health beliefs and poor adherence to self-management activities [9,10]. Malaysia has a high burden of limited health literacy in the general population [11], and asthma control is challenging by a lack of patient education, over-reliance on unscheduled visits, and lack of action plan ownership [12-14].

The use of digital technologies for internet-based information is more common in the younger age group than in the middle and older age groups [15]. Malaysia’s multigenerational household culture and strong family orientation have helped younger family members assist older generations in using digital technology to stay connected and find information [16]. The pandemic has further seen widespread adoption of digital technologies by a broader age group of users in diagnosis, prevention, and surveillance [17]. Three-fourth of Malaysians are now smartphone users, with most (60.9%) of them in the lowest income group [18]. Although health-related information-seeking behavior on the internet is greater in those with good health literacy [19], our previous qualitative work among people with limited health literacy suggests that a mobile app is a preferred medium to deliver supported self-management, including a pictogram-based asthma action plan and signposting to reliable asthma information sources.

Goals

For the aforementioned reasons, developing asthma self-management tailored to limited health literacy needs is an important context for the web-based design sprint workshop, as various studies have shown that the extensive use of pictograms, images, and prompts was appealing to participants and may improve the understanding of information in mobile apps [20-23]. However, it is essential to involve users early in the design stage, as some of the unique features that people want can be time-consuming and costly to build, and a balance may need to be found between desired features [24] and those with evidence-based recommendations [25,26].

Using a design sprint methodology, we seek to optimize user experience in app development by integrating patients into the 5-stage process of mapping, sketching, designing, developing, and testing [24,27]. We used the health literacy framework [8] to underpin the overall structure of the intervention work. The COVID-19 pandemic and physical distancing requirements meant that we had to conduct our workshop in a web-based format. In this study, we report the outcomes of the workshop deliberations and our experience of conducting a week-long remote 5-stage program attended by patients with asthma and health care professionals (HCPs).

Methods

Ethical Consideration

The workshop received ethical approval from the Medical Research and Ethics Committee of the Ministry of Health, Malaysia (ID: NMRR-19-3609-52292) and sponsorship approval by the Academic and Clinical Central Office for Research & Development at the University of Edinburgh (ID: AC20011). Informed consent was obtained from all the participants before the workshop.

Study Design

We conducted a 5-stage design sprint workshop using a web-based and qualitative research approach. We used the 5-stage design sprint process as a roadmap to develop the intervention. We adapted the methodology and constructed the workshop into five stages: (1) understanding and mapping problems, (2) sketching of solutions, (3) deciding on solutions to problems, (4) developing a prototype, and (5) testing a low-fidelity prototype [27,38]. The process was originally designed in the technology sector by the Google Ventures team for business start-up teams [27]. The involvement of the target population and early testing enhance intervention effectiveness and increase the likelihood of adoption at the implementation stage [24]. Owing to the rapid development and testing stages, this is an ideal concept for a low-resource setting, that is, time and cost [24].

Skeetaler (patient and HCP) discussions provided insights into self-management issues in stage 1, which informed mobile app development in stages 2-4. We recruited patients with asthma and limited health literacy to test the low-fidelity prototype in stage 5 and provided feedback through qualitative interviews. A low-fidelity prototype is a modeled prototype with limited technical functionality [29] that is quick to create and can be easily improved in the light of feedback in the testing stages. The details of each stage are listed in Table 1.
<table>
<thead>
<tr>
<th>Stages and objectives</th>
<th>Process</th>
<th>Adaptations for web-based delivery of the workshop</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Stage 1: understand and mapping problem</strong></td>
<td>As a team, we first discussed and agreed on the workshop’s long-term goals for the workshop’s prototype and aims through a structured discussion between the patients and healthcare professionals. We listed a list of problems relating to self-managing asthma from stakeholders (patients and clinicians) point of views. We constructed an end-to-end process of how patients cared for their asthma, and we targeted the problems we could potentially provide solutions for using the mobile app.</td>
<td>Through web conference site (Microsoft Teams), we brainstormed the long-term goal for the app and the workshop’s aim. In a separate browser, using a web-based board (Miro), we gathered the problems, potential solutions, and mapping of the target where the solutions can occur. Interviews were audio recorded during the workshop. We considered scientific literature and previous study we have conducted as expert input.</td>
</tr>
<tr>
<td><strong>Stage 2: sketch solution</strong></td>
<td>Focusing on the problems, each researcher reviewed existing ideas which we could potentially use and improve for the prototype. The individual researcher then presented their findings and the reasons why the ideas being chosen. Using this information, we then drew crude scenes with our contexts which we believed would be suitable for the app. After presenting the scenes and critical discussions, we voted on the best scene and content for the prototype.</td>
<td>Reviewing and compiling sketches of ideas were done on Miro synchronously by all researchers. We presented these sketches of ideas to the whole team on Microsoft Teams. Individually, using colorful sticky notes and marker pens, we drew the crude scenes. We took photographs of these scenes and uploaded these on Miro. Each researcher was given three blue dots for the voting, and they placed a dot on the best ideas.</td>
</tr>
<tr>
<td><strong>Stage 3: decide the solution for the problem</strong></td>
<td>The winning scenes and content comprised topics on asthma education, asthma symptoms monitoring, and supporting people living with asthma. We took the winning scenes from our sketches, and we constructed an end-to-end process (storyboard) on how these scenes and content would appear on an App. The storyboard was first constructed in text form before we transformed it visually.</td>
<td>The most voted ideas were put together, and we had another round of voting where each researcher was given a single dot, and the team leader was given three purple dots on the web-based board (Miro). The text and visual version of the storyboard was constructed as a group and through discussions on the web-based board (Miro) and Microsoft Teams.</td>
</tr>
<tr>
<td><strong>Stage 4: prototype development</strong></td>
<td>Each of the research members and the App developer was assigned rules to ensure the successful development of the low-fidelity prototype for the final day testing process.</td>
<td>On Figma, a prototype development site, the low-fidelity prototype was developed. Every researcher and the App developer completed their tasks (i.e., content and language check) within Figma. Brainstorming of prompts for the testing day was conducted on Google Sheets among the researchers. Google sheet also was where a virtual scoreboard was set up for every researcher to capture the patient’s evaluation of the prototype.</td>
</tr>
<tr>
<td><strong>Stage 5: test low-fidelity prototype</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The web-based workshop discussions were conducted on a web conference platform (Microsoft Teams), and brainstorming of the idea was conducted on a web-based board (Miro). While conducting the exercise on the web-based board, the workshop participants remained connected to the web conference site to allow ongoing discussion. The web-based board was superseded by a prototype development (Figma) site in stages 4 and 5, whereas discussions remained on Microsoft Teams. The app developer supported information technology activities. Two weeks before the workshop, one of the researchers contacted each of the participants (patients and HCPs) to assess technical skills such as the ability to log on, use a meeting platform, and logistical issues such as the quality of the internet connection.

**Setting**

The workshop, which took place between June 22 and 26, 2020, was conducted through a secure web-based meeting platform using a virtual whiteboard to facilitate information sharing between the researchers and app developers. Our original plan for a face-to-face workshop was changed to a web-based format to overcome the restriction of the order of movement because of the COVID-19 pandemic; an additional advantage was that it allowed participants from different locations and time zones to participate.

The patients were from 2 urban public primary care clinics in central Malaysia. Asthma is managed in primary care clinics, although chronic and acute care management through the provision of an asthma action plan to support asthma self-management is uncommon. Malaysia has a dual health system, public and private, where the public health system provides the leading service for the population with copayment of Ringgit Malaysia, RM 1 (US $0.23) per visit.

**Samples and Recruitment:**

**Stakeholder Discussion (Stage 1)**

A total of 3 patients and 2 HCPs who cared for asthma in the primary care settings, 2 app developers, 4 researchers from Universiti Putra Malaysia, and 1 from the University of Edinburgh were involved in the stakeholder discussion in stage 1 (Table 2).

Table 2. Summary of the stakeholders involved in each stage.

<table>
<thead>
<tr>
<th>Stakeholder</th>
<th>Stage 1</th>
<th>Stage 2</th>
<th>Stage 3</th>
<th>Stage 4</th>
<th>Stage 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Researchers</td>
<td></td>
<td>✅</td>
<td>✅</td>
<td>✅</td>
<td>✅</td>
</tr>
<tr>
<td>2. Patients</td>
<td>✅</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Health care professionals</td>
<td>✅</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. App developers</td>
<td></td>
<td>✅</td>
<td>✅</td>
<td>✅</td>
<td>✅</td>
</tr>
</tbody>
</table>

*Stakeholder present.

**Testing of the Prototype (Stage 5)**

Five patients, recruited from the Klang Asthma Cohort, participated in testing the prototype at stage 5 (Table 2). The Klang Asthma Cohort database is one of the research outputs of EESPIRE (National Institute for Health Research Global Health Research Unit on Respiratory Health) in Malaysia. The database contains 1280 people with asthma recruited from...
primary health care clinics in the Klang district. They provided consent to be called with invitations to participate in asthma-related research. Inclusion criteria for patients invited for this study were physician-diagnosed asthma, aged >18 years, smartphone user, limited health literacy, and were assessed by screening using the Bahasa Malaysia language version of the Health Literacy-Q47 scale [30]. The initial Health Literacy-Q47 scale [31] was translated and validated in Malaysia with a Cronbach α of 0.86 [30].

**Data Collection**

Demographic information was collected from the database of patients who agreed to participate. Stakeholders’ discussions in stage 1 focused on challenges by patients and HCPs around (1) asthma education, (2) asthma self-management, (3) monitoring of symptoms, (4) emotional support or lifestyle advice, (5) social support, and (6) clinic set up (Multimedia Appendix 1).

In stage 5, we tested the prototype with 5 patients to assess its utility and usability using a set of semistructured questions in a concurrent think-aloud manner (Multimedia Appendix 2). During this session, HS, the main interviewer, guided the process. Four other researchers, PYL, SSQ, ATC, and JW, observed the interview while the 2 app developers, Adit Goh and Muhammad Marzuqi, managed the technical aspects of the sessions. The interviews took 1 hour and were conducted in Bahasa Malaysia, the patients’ preferred language.

Qualitative interviews were audio recorded. Other web-based discussions and browsing activities were video recorded, and web-based board exercises were captured and archived as described in Table 1. All interviews were transcribed verbatim.

**Data Analysis**

For this qualitative study, we used thematic analysis to obtain rich data from the stakeholders’ discussions in stage 1 and the interviews in stage 5. The texts were analyzed iteratively using a deductive thematic analysis approach, as outlined by Braun et al [32]. The deductive thematic analysis seeks to answer the researcher’s theory or analytical interest within the topic [32]. Phases in the thematic analysis included (1) familiarization with the data by reading and rereading and noting down initial ideas (memoing), (2) develop a coding (HS and JW) of one interview and comparing decisions to agree on standardizing the coding framework before coding all the transcripts, (3) discussing emerging themes with the research team, (4) reviewing themes with the wider research team and generating a map of the analysis (HP, SSQ, PYL, ATC, or FY), (5) defining themes iteratively, and (6) presenting the deductive analysis with a selection of extracts. The data were organized using NVivo 11 (QSR International) qualitative data analysis software (HP and FY).

**Results**

**Participants’ Characteristics**

Five patients (including 3 who attended stage 1) attended stage 5 (prototype testing). Table 3 summarizes the demographics of the patients involved in stage 5.

<table>
<thead>
<tr>
<th>ID</th>
<th>Age (years)</th>
<th>Gender</th>
<th>Education level</th>
<th>Health literacy score</th>
<th>Use of pictorial asthma action plan at 6 months</th>
<th>Access to a digital device</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>44</td>
<td>Female</td>
<td>Secondary</td>
<td>36</td>
<td>Yes</td>
<td>Smartphone and PC</td>
</tr>
<tr>
<td>P2</td>
<td>36</td>
<td>Male</td>
<td>Tertiary</td>
<td>32</td>
<td>No</td>
<td>Smartphone</td>
</tr>
<tr>
<td>P3</td>
<td>40</td>
<td>Female</td>
<td>Tertiary</td>
<td>17</td>
<td>Yes</td>
<td>Smartphone and PC</td>
</tr>
<tr>
<td>P4</td>
<td>38</td>
<td>Male</td>
<td>Tertiary</td>
<td>21</td>
<td>No</td>
<td>Smartphone</td>
</tr>
<tr>
<td>P5</td>
<td>19</td>
<td>Male</td>
<td>Secondary</td>
<td>31</td>
<td>No</td>
<td>Smartphone and PC</td>
</tr>
</tbody>
</table>

*Score less than 33 is considered as limited health literacy.

**The Outcomes of Each Stage**

**Stage 1: Understanding and Mapping Problems**

Overall, 3 patients and 2 HCPs (a family physician and a medical officer from Klang district) contributed to the stakeholder’s discussion. The stakeholder discussion themes were categorized as relating to individuals, family and friends, society, and systems (Multimedia Appendix 3). The key problem used to inform the app design was education sources for asthma and support in the community, enabling self-management using pictorial action plans, reminders for medications, and asthma reviews or appointments. The log of history of asthma control, preventer intake, and information on expected best peak expiratory flow rate were features that could support patients during asthma review or appointment to discuss with their HCPs.

**Stage 2-4: Sketching, Designing, and Developing the Prototype**

Informed by the stakeholder discussion and findings of our previous qualitative study, we worked through the stages of sketching solutions and designed and developed the prototype (Multimedia Appendix 4). Through a round of voting in stage 3, solutions supporting self-management based on evidence-based practice were selected [3]. All winning solutions were clustered around four aspects of care: (1) education, (2) supporting self-management, (3) supporting behavior change, and (4) social support (Table 4). We created a storyboard for the prototype, and we developed the prototype app based on the storyboard, which was then tested in stage 5.
Table 4. Asthma App content and design features.

<table>
<thead>
<tr>
<th>Main theme and section</th>
<th>Content</th>
<th>Features</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Education</strong></td>
<td>- Information in text and videos about asthma, symptoms, triggers, how the diagnosis is made, exacerbations and myths around asthma attack. Other information includes types of medications used to treat asthma, its function, and potential side-effects of the medications. There will be video-based instructions on the inhaler technique.</td>
<td>- The links to the Ministry of Health portal on asthma was provided under specific headings to facilitate the search for reliable information.</td>
</tr>
<tr>
<td><strong>Supporting self-management</strong></td>
<td>- Patients indicate any experience of asthma symptoms in the last 24 hours, which will translate into control and prompts to check the action plan.</td>
<td>- Tick-box list of potential asthma symptoms; ticking any one symptom will prompt a pop-up on advice to look at an action plan with a click button.</td>
</tr>
<tr>
<td>Self-monitoring of symptoms</td>
<td>- A pictorial asthma action plan was used. Illustrations and wordings were validated in a series of discussions with stakeholders.</td>
<td>- List of zones are displayed, and patients choose which zone are appropriate for them.</td>
</tr>
<tr>
<td><strong>Supporting behavior change</strong></td>
<td>- Patients provide information about medications and appointment reminders which will trigger a reminder system at the timing of choice.</td>
<td>- Matrix of images of medications used and drop-down menu for frequency and timing.</td>
</tr>
<tr>
<td>Asthma medication and appointment reminder</td>
<td>- Asthma control and medication uptake will be recorded in the diary, including best PEFR*.</td>
<td>- Monthly calendar, which displays asthma control and adherence.</td>
</tr>
<tr>
<td><strong>Others</strong></td>
<td>- Achieving good asthma control and medication adherence will be translated into points.</td>
<td>- Display of scale of points achieved for good asthma control and adherence.</td>
</tr>
<tr>
<td>Social support</td>
<td>- Information regarding support groups for asthma in Malaysia</td>
<td>- The links to various support groups available in Malaysia.</td>
</tr>
</tbody>
</table>

*PEFR: peak expiratory flow rate.

The entire process is illustrated in Figure 1, and the decisions on the prototype are summarized in Table 4. The app was written in the Malay language.
Stage 5: Testing Low-Fidelity Prototype

Patients who attended stage 1, along with 2 other patients, attended stage 5. Results are presented under the 2 main themes of utility (i.e., app influence or support self-management) and usability (ease of use).

Utility

Patients commented that the app influenced the decision to self-manage in four ways: offering information, providing an accessible asthma action plan, motivating and supporting improved medication adherence, and promoting behavior change through a reward system.

Offering Information

Patients considered that the app provided essential information regarding asthma and how to manage it. P4 explained, “the information about asthma in the app is interesting and informative.” Although many were comfortable reading
text-based information, some preferred audio-visual formats such as videos. P5 explained, “the information about asthma, maybe it can be in the video, it’s more interesting than just text.”

Providing Accessible Asthma Action Plans

Patients felt that having an action plan on the phone made the plan accessible when needed. As P1 described, “when you need the plan, you just open the App in your phone and click on the plan [action], to see it.” In this format, patients considered it easier to access and use the app-based plan than the paper-based action plan, which they may not carry unless they attend medical appointments.

Motivating and Supporting Improved Medication Adherence

The medication reminder function of the app was viewed as a good support for achieving good adherence to daily preventers. P5 stated, “It will be difficult not to remember taking the medications because of the reminder, and because I use the phone frequently, it is hard to ignore the reminder (chuckled).”

Promoting Behavior Change Through a Reward System

The app was designed to encourage behavior change through a positive reward system, where good asthma control and adherence to twice daily preventive inhalers would be awarded points, and the cumulative points were visualized clearly. Patients liked this approach. P1 was incredibly excited to see the reward points on the App: “wow, there is a reward points, this is great!” This excitement was shared with other patients who preferred to see the tangible results of their actions. P3 elaborated on how the reward system could influence behavior: “That’s nice when I get points for taking the medications. I do want to see that I accumulate points and the scale moved further. And I can only do this if my control is good and if I take my medications.”

Usability

The patients could easily comprehend the information and instructions in the app. P2 elaborated on how he achieved this: “the instructions are accompanied with illustrations. It makes it easier to understand it.” Although patients liked the use of illustrations and fewer words, the small font size used was challenging for some. P1 said:

[The] writing is small. I tried to put on my glasses, I still can’t see it (chuckled).

We used cartoon-based illustrations of the medications and in the steps of the asthma action plan. Some studies have suggested that the pictorial asthma action plan may be useful for patients with asthma other than adults. P3 suggested:

I think the illustrated plan can be appealing and useful for children and their carer. It’s very easy to understand.

Patients pointed out that a lack of navigational symbols meant that it was not always clear how to move from one interface to another. P4 stated his confusion:

There is no sign or indication on what to do next. I was a bit lost on what should I do now. Perhaps an arrow would help to tell that I can move forward.

Otherwise, patients were mostly satisfied with the simple layout. P1 gave an example of this:

In terms of the layout, it’s quite easy to navigate around the App. It’s ok for me.

The time spent using the app varied between 10 and 45 minutes. Some (younger) patients seemed comfortable navigating from one interface to the other and were keen to click buttons to explore the app functions. In contrast, others were dependent on symbols or prompts to navigate, which the app lacked at the testing stage.

The language used in the app was generally satisfactory, although there was a linguistic misunderstanding of breathlessness and wheeze in the Bahasa Malaysia language. P4 described his confusion on the Bahasa Malaysia words for breathlessness and wheeze:

Mengalami sesak nafas (breathlessness) and lelah (wheezing), are different? I thought it’s the same thing?

After the Workshop

The design was refined and finalized after testing in stage 5 (Figure 2).
Discussion

Principal Findings

We conducted a design sprint workshop and employed a web-based format to ensure the safety of researchers and patients during the global pandemic. In this 5-stage workshop, we developed a low-fidelity prototype based on theoretical frameworks and refined it based on patient feedback during the design and testing stages. Patients described the resultant app to influence their ability to self-manage in four ways: offering information, providing accessible asthma action plans, motivating and supporting improved medication adherence, and promoting behavior change through a reward system. Specific usability issues were related to navigation, comprehension, and layout.

Strengths and Limitations

The involvement of stakeholders and the multidisciplinary approach at the development stage in the design sprint process are among the strengths of this study, which may increase the chances of the intervention meeting the needs of the target population. The 5-stage design sprint structure allowed the development and testing process to be performed quickly and efficiently at a low cost, which would likely be favorable in low-resource settings. Constructing a low-fidelity prototype offers many advantages in the initial stages of prototype development. It allows a quick gathering of requirements, ideas, and concepts and can be built rapidly [29]. The disadvantage was that the low-fidelity prototype lacked some core functionality (such as navigation features), so that the patients on day 3 gave feedback on a limited version of the app. Nevertheless, the feedback was beneficial and enabled the app to be refined after the workshop to produce a high-fidelity prototype.

The web-based approach connected people in different geographical locations and ensured safety during the global pandemic. We recognized that we do not have any participants aged >50 years, however, because this approach may be more appealing to younger age groups, although with limited health literacy, and it may not reflect the feasibility of using web-based methods for older age groups. We overcame limited internet access by providing an internet data voucher; however, we had to exclude those with no access to any digital devices. We provided training on the various platforms to be used in the workshop, thus overcoming the lack of digital skills. These strategies may assure researchers or intervention developers working in countries or settings with high levels of limited health literacy that this web-based methodology is of value.
The pandemic context may have explained the relatively small number of participants recruited during the testing stage. Some participants found it challenging to commit uninterrupted time to a web-based workshop while being locked down at home with their domestic or caring at home-schooling responsibilities. For comparison, face-to-face intervention design workshops have been reported with 14 participants in 5-day workshops [33] and 38 participants over 6 weeks [34].

Adaptation of the Design Sprint Workshop to a Web-Based Format

Patients with asthma and HCPs were recruited for a workshop in March 2020, but this could not occur because of the compulsory lockdown imposed by the local authorities in response to the COVID-19 pandemic. Therefore, we adapted the workshop to the challenges of a web-based format and its potential impact on participants’ research experience [33]. A high-speed internet connection and technical skills in conducting this workshop were vital. To overcome some of these practical issues, we supported all participants with mobile web-based access through a RM 10 (US $2.42) internet data voucher to ensure that the participants would not bear the cost of internet access. Participants’ experience with technologies was around social media that is Facebook, video call, that is, WhatsApp, and information searching platforms, that is, Google and YouTube. We found a lack of experience with videoconferencing platforms and the software we planned to use during the testing day. Thus, we conducted training sessions for all participants to avoid technical problems during the workshop.

In the context of interviews, the literature suggests that web-based data collection can produce data of similar quality to face-to-face interviews [35]. Although using a web-based platform to interview patients was a new experience for the researchers, we found that the web-based programs eased discussions, and interviews took place quickly and effectively. Compared with traditional qualitative interviews, one advantage was that other researchers could observe the interview sessions on the web-based platform, and they could make concurrent fieldnotes. From the patient’s feedback, although they knew they were being observed by additional researchers, being at their own home helped them forget about being observed and anxious.

In web-based discussions and interviews, dictation software has been used to capture audio data in text format, thereby avoiding transcription errors [36,37]. However, this was not possible in our context because the medium of interaction was the Bahasa Malaysia language, and the extensive use of colloquial language made it impossible to use any dictation software. Conducting research on the web raises concerns about participants’ confidentiality and data security. We ensured that entry to the workshop was password-protected to control access to maintain the participant’s confidentiality securely. The recordings were stored in a secure manner. For example, files from the workshop were encrypted and stored in a secure research data storage facility.

Web-Based Design Workshop and the Context of Limited Health Literacy in a Low-in-Middle-Income Country

Our app focused on designing a pictorial asthma action plan as a core strand of tailoring supported self-management for people with limited health literacy. Other features were a simple language for symptom assessment, education and information resources, provision of visual and audio medication reminders, and practical behavior change strategies such as a reward system. A clear message from our previous qualitative work was that participants wanted an interactive approach to support the asthma action plan with few words and clear pictures. Our original plan was to provide a paper-based pictorial action plan, but as it is not interactive, we reconsidered potential formats and decided to deliver the pictorial asthma action plan using a mobile app. Using a mobile app was seen as promoting a sense of autonomy to feel empowered in managing asthma.

Although previous reviews have reported a lack of interest in action plans [21], others have reported on the keenness of people to use action plans in mobile apps [38], although none have explored plans tailored for people with limited health literacy or the innovative pictorial representation of actions in a mobile app. In the United States, a study found that action plans were written at the literacy level of sixth-grade (11 to 12-year-olds), which will be a challenge to those without formal education or only receiving primary school education [39]. The same study also found that more graphics within an action plan may be needed to increase the ease of use [39]. In our web-based design workshop, the extensive use of images, icons, and the use of simple language were among the strategies used to overcome the challenge of understanding a written asthma action plan.

Recommendations for Practice, Policy, and Research

We outlined recommendations for practice, policy, and research based on this study in Textbox 1. On a practical level, to help researchers’ concentration throughout the 5 days of the 7-hour workshops, we included frequent breaks and provided high-energy snacks. Each session was either 1 hour long with a 15-minute break or 45 minutes long with a 10-minute break. Committing to time in a workshop alone in front of the monitor can be challenging and mentally draining, so a week before the workshop, each researcher received a supply of high-energy snacks through the post. We also provided colored sticky notepads and permanent markers with similar tip sizes to ensure that all scanned sketches and writings were clear when uploaded on the web-based discussion board.
Textbox 1. Recommendations for practice, policy, and research.

<table>
<thead>
<tr>
<th>Practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Although some participants only join the workshop for short periods, researchers and technical colleagues have to concentrate on the web for long periods. Adequate breaks, attention to nutrition, and general comfort are essential.</td>
</tr>
<tr>
<td>The web-based platforms may be unfamiliar to many participants; training before the workshop gives confidence and helps reduce technical problems on the day.</td>
</tr>
<tr>
<td>Owing to the relatively low cost and a short time spent from development to testing, the web-based design sprint methodology may be suitable for low-resource settings.</td>
</tr>
<tr>
<td>Remote conduct ensured that high-risk stakeholders were shielded during a pandemic and overcome geographical barriers.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Policy</th>
</tr>
</thead>
<tbody>
<tr>
<td>The process is a sprint so that the end product can be developed to a short timescale to meet pressing deadlines.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Research</th>
</tr>
</thead>
<tbody>
<tr>
<td>The feasibility study of conducting a more extensive scale web-based intervention design program is necessary to ensure its practicality.</td>
</tr>
</tbody>
</table>

Conclusions

Working with people with limited health literacy enabled the development of an app that could support them in self-managing their asthma. Specific components included sources of information on asthma, pictorial asthma action plan, simple language, audio-visual prompts, and rewards for supporting adherence to daily therapy and scheduled reviews. Despite practical challenges, a 5-day web-based design workshop proved to be manageable, enabling meaningful engagement from patients and HCPs so that a prototype is now ready for feasibility testing.

Acknowledgments

This research was commissioned by the UK RESPIRE using UK Aid from the UK Government. The views expressed in this publication are those of the authors and not necessarily those of the National Institute for Health Research or the UK Department of Health and Social Care. The RESPIRE collaboration comprises UK grant holders, partners, and research teams as listed on the RESPIRE website. The authors are grateful to the study subjects for participating in this study. The authors would like to thank the experts from Pocket Pic! Sdn Bhd, Mehdi Khalid IA, Goh A, and Zainal MM for their support in the conduct of this study.

Authors’ Contributions

HS, HP, PYL, SSG, and JY were involved in formulating the ideas for the study. HS and JW planned and conducted training for the participants. HS, PYL, SSG, ATC, and JW conducted the workshop and collected the data. HS conducted data analysis, and all authors were involved in data interpretation. HS drafted the manuscript. All authors critically revised the manuscript for intellectual content. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Prompts for stakeholder discussion.
[DO CX File : 22 KB Multimedia Appendix 1]

Multimedia Appendix 2

Utility and usability prompts.
[DO CX File : 21 KB Multimedia Appendix 2]

Multimedia Appendix 3

Themes from the stakeholders’ discussion.
[DO CX File : 25 KB Multimedia Appendix 3]
Multimedia Appendix 4
Sages 2–4.

References


**Abbreviations**

HCP: health care professional

RESPiRE: National Institute for Health Research Global Health Research Unit on Respiratory Health
Edited by R Kakafika; submitted 14.12.20; peer-reviewed by L Kayser, E Arden-Clarke; comments to author 14.02.21; revised version received 21.03.21; accepted 06.05.21; published 09.09.21


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PMD: 

©Hazi Salim, Ping Yew Lee, Suzilina Sharif-Ghazali, Ai Theng Cheong, Jasmine Wong, Ingrid Young, Hilary Pinnock, RESPIRE Collaboration. Originally published in the Journal of Medical Internet Research (https://www.jmir.org), 09.09.2021. This is an open-access article distributed under the terms of the Creative Commons Attribution License (https://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in the Journal of Medical Internet Research, is properly cited. The complete bibliographic information, a link to the original publication on https://www.jmir.org/, as well as this copyright and license information must be included.
Appendix 22 Design Sprint workshop: Participant information sheet and consent form

Participant Information Sheet

Developing, refining and feasibility study of a mobile-based pictorial asthma action plan for people with limited health literacy.

(Design Sprint workshop)

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Contact us if there is anything that is not clear, or if you would like more information. Take time to decide whether or not you wish to take part.

An NIHR Global Health Research Unit on Respiratory Health (RESPIRE) at the University of Edinburgh project.

www.ed.ac.uk/usher/respire

This research was commissioned by the National Institute of Health Research using Official Development Assistance (ODA) funding. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.
**What is the purpose of the study?**

Being able to self-manage own asthma with the support of written action plans own asthma has been proven to improve asthma control and reducing acute asthma attacks. However, globally it can be challenging to implement self-management for people with limited health literacy.

The purpose of this study is to develop, refine and test a mobile application for asthma self-management. The research is necessary to provide information for future study on the effectiveness of this intervention for improving asthma self-management.

This study is divided into two phases:

**Phase 1: A workshop to design and refine a prototype app**

**Phase 2: A feasibility study**

The subject of this document relates to Phase 1, where we will convene a one-week online design workshop to design, develop and test the prototype. A total of 5 participants like you from your clinic will be participating in this study.

**Why have I been invited to take part?**

You have been asked to take part as you are a patient with asthma that has been following up at Bandar Botanic Health Centre, Klang, Selangor.

**Do I have to take part?**

No, it is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. Deciding not to take part or withdrawing from the study will not affect the healthcare that you receive, or your legal rights. Before participating you should consider if this will affect any insurance you have and seek advice if necessary.

**What will happen if I take part?**

If you agree to take part in this study, you will be invited to help with the design workshop conducted online. The goal of the workshop is to design, identify the problems users might face when using the intervention, provide solution for this and try out the app.

You may be asked to help on two days, or just for one day. You may also need to take part in a pre-workshop training (approximately 1 hour). The research assistant will call you to explain about the study protocol prior to it. If you agree to participate, the researcher will ask you to give a verbal consent which will be recorded.

- **If you agree to help for 2 days**: Five people with asthma will be invited to attend the first two days of the workshop. Both days will be all-days (9 am – 4 pm). The day will involve discussions in small groups with other people with asthma, doctors or nurses, researchers and app designers.
- **If you agree to help on one day**: Five people with asthma will be involved in trying out of the app. This will take an hour, and you will be asked to try the app and tell us what you think. There will be a researcher and an app developer asking your opinion.
The discussions and comments will be audio-recorded for data analysis.

**Is there anything I need to do or avoid?**

No, there is nothing that need to do or avoid.

**What are the possible benefits of taking part?**

You will be able to contribute significantly to the development of an intervention to improve asthma self-management. The researcher will also be able to contribute to the larger body of medical knowledge in the field of asthma self-management.

**What are the possible disadvantages of taking part?**

You would probably need to spend an extra time during the online meetings.

Participating in this study involves commitment on the part of the patient, and if this prove tiring, the researcher will be sensitive to the need for a break.

There will not be any impact on insurance e.g. private medical insurance or travel insurance for your participation in this study.

**What if there are any problems?**

If you have a concern about any aspect of this study, please contact the researchers stated below who will do their best to answer your questions.

- Dr Hani Syahida Salim (011-26089233)
- Professor Lee Ping Yein (010-2267698)
- Associate Prof Dr Sazlina Shariff Ghazali (012-2325850)

**What will happen if I don’t want to carry on with the study?**

Your participation in this study is voluntary. You do not have to be in this study if you do not want to. If you volunteer to be in this study, you may withdraw from it at any time. This means that you will no longer be taking any further active part in the research. However, you will have the option of withdrawal from:

(i) all aspects of the study but continued use of data collected up to that point, or
(ii) all aspects of the study with removal of all previously collected data.

**What happens when the study is finished?**

Data from the study will be archived and may be transmitted outside the country for the purpose of analysis, but your identity will not be revealed at any time. All the consent forms, clinical report forms and questionnaires will be stored in a locked filing cabinet accessible only by the researcher team for 5 years. After this time information will be shredded and disposed in secure bins. The participants will not be identified individually in publications or report writing. Participants are allowed to access their results from the study, if they wish for three months after completion of the study. A summary of final report will be submitted within a year after completion to the study to the
Malaysian Medical Research Ethics Committee and all findings will be notified to the University of Edinburgh.

Non-identifiable data from this project may be deposited into a research data repository at the University of Edinburgh to allow (through managed access arrangements) knowledge sharing and learnings about this study. The University of Edinburgh provides its researchers (and their collaborators) two alternative services for sharing and archiving of data. DataShare is an open access repository and all data is freely available. DataVault is a restricted access archive controlled by the data owners and appropriate for sensitive information.

**Will my taking part be kept confidential?**

All the information that is collected about you during the course of the research will be kept highly confidential and there are strict laws which safeguard your privacy at every stage. The information on the study database will not have any information that could identify you – your record will be known by a code number and the key to the code will be kept securely on a separate password-protected computer. Only the sponsor, researchers, regulatory authorities and Research & Development auditors will have access to the data.

**What will happen to the results of the study?**

We will present the findings at conferences, and publish them in academic journals and as part of a PhD thesis - but your name will not be included and the information you give us won’t be linked to you.

A summary of the results will be sent to you by post if you are interested and request for a copy.

**Who is organising and funding the research?**

This study is sponsored by the National Institute for Health Research, University of Edinburgh, United Kingdom for this study based in Malaysia. This study has been organised by researchers from Universiti Putra Malaysia as well as healthcare professionals from various healthcare facilities in the Klang district.

I am supported by PhD studentships from the NIHR Global Health Research Unit on Respiratory Health (RESPIRE). RESPIRE is funded by the National Institute of Health Research using Official Development Assistance (ODA) funding.

**Who has reviewed the study?**

This study is registered in the Malaysian National Medical Research Register and has been reviewed and approved by the Medical Research & Ethics Committee, Ministry of Health Malaysia. It has been approved by Academic and Clinical Central Office for Research & Development - Joint office for The University of Edinburgh and Lothian Health Board (ACCORD) for the University of Edinburgh’s Research sponsorship.

**Researcher Contact Details**

If you have any further questions about the study, please contact:
- Dr Hani Syahida (011-26089233) or email on: hanisyahida@upm.edu.my
- Professor Lee Ping Yein (010-2267698) or email at: yein@upm.edu.my
<table>
<thead>
<tr>
<th>Participant ID:</th>
<th>Centre ID (if applicable)</th>
</tr>
</thead>
</table>

- Associate Prof Dr Sazlina Shariff Ghazali (012-2325659) or email at: sazlina@upm.edu.my

**Independent Contact Details**

If you would like to discuss this study with someone independent of the study or if you have any questions about your rights as a participant in this study, please contact:
The Secretary, Medical Research & Ethics Committee, Ministry of Health Malaysia at 03-22874032.

**Complaints**

If you wish to make a complaint about the study please contact:
The Secretary, Medical Research & Ethics Committee, Ministry of Health Malaysia at 03-22874032.

**Privacy notice**

The University of Edinburgh is the sponsor for this study based in Malaysia. The Sponsor has overall responsibility for the running of the study. To follow the United Kingdom’s data protection regulation, we must inform you of how we will use and store your personal data.

As a university, we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study. We will use information from you and/or your clinical records in order to undertake this study. The sponsor will keep identifiable information about you for 5 years after the study has finished.

The University of Edinburgh will act as the data controller for this study. This means that they are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.
CONSENT FORM

Study Title: Developing, refining and feasibility study of a mobile-based pictorial asthma action plan for people with limited health literacy
(Design Sprint: patient)

Please initial box:

1. I confirm that I have read and understand the information sheet (1May2020 and Version 3.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these questions answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my medical care and/or legal rights being affected.

3. I give permission for my personal information (including name, address, date of birth, telephone number and consent form) to be passed to the University of Edinburgh and Universiti Putra Malaysia for administration of the study.

4. a) I agree to participate in the discussion within this design workshop (Day 1)  
   b) I agree to participate in the testing day within this design workshop (Day 5)

5. I agree the discussion/comments being audio recorded during the workshop

6. I agree to my audio recorded discussion being transcribed by a third-party contractor

7. I am fully aware that the results of this project will be used for scientific purposes and may be published. I agree to this, provided my privacy is guaranteed

8. I agree that my non-identifiable data from this project may be deposited into a research data repository at the University of Edinburgh to allow knowledge sharing and learning about this study

9. I agree to take part in the above study

Name of Person Giving Consent
Date
Signature

Name of Person Receiving Consent
Date
Signature

1x original - into Site File; 1x copy - to Participant; 1x copy - into medical record

An NIHR Global Health Research Unit on Respiratory Health (RESPiRE) at the University of Edinburgh project. www.ed.ac.uk/asher/respire

This research was commissioned by the National Institute of Health Research using Official Development Assistance (ODA) funding. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.
# Appendix 23 Utility and usability prompts: testing of the prototype (Stage 5)

### Utility prompts

| Q1: Is the information in this App useful? |
| Q2: Based on the information in this application, do you know what to do if you have asthma symptoms? |
| Q3: Does the information in this App help you to take your daily medications? |
| Q4: Will the information in this App motivate you to control asthma? |
| Q5: Would you recommend this application to someone with asthma? |

### Usability prompts

| Q6: Do you understand the information displayed in this application? |
| Q7: Do you understand the language used in this application? |
| Q8: Is it easy for you to browse this application? |
| Q9: Is the layout in this application appropriate? |
| Q10: Is the illustrations or pictures in this App interesting? |
| Q11: Will you continue to use this application? |

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Appendix 24 The complete Design Sprint process

Stage 1
Understanding & mapping problems

Stage 2
Sketching solutions.

Stage 3
Deciding on solutions to problems.

Stage 4
Prototype development.

Stage 5
Prototype testing and evaluation.

Outcome
Refining of prototype after Design Sprint process.

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Appendix 25 The Digital Health webinar poster

IS MALAYSIA READY FOR A DIGITAL TRANSFORMATION IN HEALTHCARE?

Saturday 31 JULY 2021
10am - 12pm

Programme

1000 - 1015 Opening and Introduction
1015 - 1030 Accelerating digital transformation in healthcare: pitfalls and opportunities in Malaysia
1030 - 1045 Digital health strategies for management for chronic respiratory disease: the case of asthma and COPD
1050 - 1105 Future of digital health in Malaysia: forging partnership with the industry
1110 - 1120 Development of mobile application for palliative asthma action plan (m-PAAP) for people with limited health literacy
1125 - 1200 Panel Discussion

Register here for FREE:

bit.ly/RESPIReDigital

Moderator

Aj/Prof. Dr. Cheong Ai Theng
Head of Department, Family Medicine, UPM.

Speakers

Dr. Izzuna Noelia Ghazali
Head of Horizon Scanning, Comm and Info Unit MakteM, Mokhi.

Aj/Prof. Dr. Andrea Ban Yu-Lin
Senior Consultant Physician & Pulmonologist, HCTM UKM. Chairperson, QPG: Management of Asthma in Adults.

Aj/Prof. Dr. Shafiee Jafmi
Drazer & Communication Systems Engineering, UPM.

Dr. Hamid Sazhida Salim
PhD Candidate, University of Edinburgh. Family Medicine, UPM.

ORGANISED BY RESPIRE MALAYSIA
Appendix 26 Part of the proposal for the prototype app feasibility study

Non-CTIMP Study Protocol
Developing, refining and feasibility study of a pictorial asthma action plan mobile application for people with limited health literacy in Malaysia (m-PAAP)

| The University of Edinburgh and/or Lothian Health Board |
| ACCORD |
| The Queen's Medical Research Institute |
| 47 Little France Crescent |
| Edinburgh |
| EH16 4TJ |

**Protocol authors**
- Dr. Hani Syahida Salim
- Professor Hilary Pinnock
- Dr. Ingrid Young
- Professor Lee Ping Yein
- Professor Sazlina Shariff Ghazali

**Funder**
NIHR Global Respiratory Health (RESPIRE) Unit

**Funding Reference Number**
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**Chief Investigator**
Professor Aziz Sheikh

**Sponsor number**
AC20011

**REC Number**
Medical Research & Ethics Committee, Ministry of Health Malaysia: NMRR 52292

**Project registration**

**Version Number and Date**
Version 3.0; 1 October 2020

**Amendment classification and number:**
- Summary of change(s)
  - Amendment 2: At the end of document (based on REC feedback and recommendations)
1. Introduction

1.1 Summary of the overall PhD illustrating where this project sits

This application relates to project 3 of my PhD ‘Developing, refining and feasibility study of a pictorial asthma action plan mobile app for adult asthma with limited health literacy to improve self-management (m-PAAP)’ (illustrated in blue on the schema below).

Supported asthma self-management for asthma (including action plans and regular review) improves health outcomes. However, these benefits may not be realised by people with limited health literacy. Consideration should be given to whether tailored interventions such as the use of visual aids can enable asthma self-management.

Figure 1 Flow diagram of the projects of the PhD

As depicted in the schema above, my PhD includes three projects:

1. In the first project, findings from a systematic review have found gaps in the asthma self-management among people who have limited health literacy in terms of the quality of the interventions and the components which were used to achieve behaviour change.

2. The second project was a qualitative study among people with limited literacy who have asthma. This gave an in-depth understanding of their perceptions of asthma and how they decide on self-management actions.

3. In the third project (the subject of this protocol), we will develop a pictorial asthma action plan delivered using a mobile application and explore the feasibility of this intervention.

Note: UK ethical approval is requested for the feasibility phase (Phase 2: section 4.3). Our sponsor does not require UK approval for the design/development phase (Phase 1: section 4.2).
3. Study aims and objectives

3.1 Aim

We aim to develop, refine and assess the feasibility of a pictorial asthma action plan delivered through a mobile app for adults with asthma and limited health literacy and assess potential outcomes for a trial.

3.2 Objectives

1. To develop and refine a prototype pictorial asthma action plan mobile app to be used in clinical practice to deliver guideline-recommended supported self-management for people with limited health literacy

2. To determine the feasibility, acceptability and usability of a pictorial asthma action plan in a mobile app in adults with asthma from the perspective of:

2.1 Patients

   2.1.1 to explore the facilitators and barriers (including technical factors) of using a pictorial asthma action plan in a mobile app to support asthma self-management among people with limited health literacy

   2.1.2 to explore the features of the pictorial asthma action plan mobile app that patients would like to see and will continue to use on an app

2.2 Healthcare professionals

   2.2.1 to explore the facilitators and barriers to using a pictorial asthma action plan in a mobile app in clinical practice to support asthma self-management among people with limited health literacy

3. To determine the baseline measurements and potential magnitude of change in health and process outcomes to inform a future trial
4.3 PHASE 2: Feasibility of the prototype

**Note:** As per request by our sponsor, UK ethical approval is requested for the feasibility phase (Phase 2: section 4.3)

| Covid-19 pandemic: compliance with social distancing regulations | To ensure the safety of participants and researchers, we will comply with all social distancing regulations in force at the time of undertaking the fieldwork for this feasibility study. The study requires ownership of a smartphone, and much of the interaction was already planned to be conducted remotely. Where face-to-face task were planned remote alternatives are indicated at relevant points in the description below. For example, we will use phone or video calls to explain about the study, on-line forms to obtain consent and phone or video-calls to conduct observations and interviews. |

Objective 2: To determine the feasibility, acceptability and usability of a pictorial asthma action plan in a mobile app in adults with asthma from the perspective of 1) Patients and 2) Healthcare professionals.

We will be using mixed methods in a 3-month feasibility study (see Table 4 for a summary of study design) to test a mobile App.

The main content of the App is the pictorial asthma action plan, and personalised information including medications and appointments. There will be options for daily asthma diary completion including PEF. We will provide useful links such as the Ministry of Health’s health portal for asthma [http://www.myhealth.gov.my/asma-3/](http://www.myhealth.gov.my/asma-3/), videos to demonstrate use of various inhalers, app’s tutorial and Department of Environment’s air-pollution index monitors [http://apims.doe.gov.my/public_v2/home.html](http://apims.doe.gov.my/public_v2/home.html).

4.3.1 Study setting

The study will take place at a public primary health care clinic, Bandar Botani Health Clinic Klang, Selangor, Malaysia.

4.3.2 Study population

**Eligibility**

**Inclusion criteria**

1. Patients with physician-diagnosed asthma
2. Aged 18 years and above (based on Malaysian Age of Majority Act 1971 that allows them to make a medical decision on their own.[35])
3. Patients who use an inhaled corticosteroid (preventer inhaler) on a daily basis.
4. People with limited health literacy (based on an assessment of their health literacy level using a validated health literacy scale (HLS: Appendix 1)).
5. Patients who are android phone users (by far the commonest phone used in this population)

Exclusion criteria

1. Any person who is acutely unwell and requiring emergency management at the time of the consultation.
2. People unable to participate in interviews (e.g., severe hearing/speech impairment) in one of the widely used languages in Malaysia (Malay, Mandarin or English).
3. Unable to give informed consent (e.g., cognitive impairment, learning disability)
4. At the discretion of the doctor because of over-riding medical conditions or social issues (e.g., terminal illness, recent very distressing life event)

4.3.3 Sample size

As this is a feasibility study, a sample size calculation is not required. We will recruit a total of 35 participants as this number is adequate to inform us about the feasibility of delivering the pictorial asthma action plan intervention, as well as to assess the recruitment process and attrition.[36]

4.3.4 Recruitment to the feasibility study

Patient

We will recruit a total of 35 adults with asthma. Identification of the participants based on the eligibility criteria will be made through the Klang Asthma Cohort database who are based at the Botanik Health Clinic (see section 4.2.3 for explanation of the Klang Asthma Cohort. Besides the eligibility criteria, we will purposively be sampled based on all range of ages, ethnicity and education level). In the event that we have more than one participant with the exact same eligibility criteria, we will randomly sample the participant. The potential participants will be contacted by a member of the research team initially with a phone call. An explanation about the study (feasibility study, including the qualitative) will be made. We will provide an information pack containing; i) the participant information sheet explaining about the feasibility and qualitative study. Participants will be given at least two weeks to decide about participating. If they are interested to join study, they will make a call to one of the research members.
Participants will give written consent by signing the consent form in hardcopy or online, the flexibility we will give the participants in-line with the social distancing measures after they understand about the study process and are willing to participate. For the hardcopy version, participants may print and post it back to the researcher. For online form, participants may be given the option to complete the consent form online and email it back to the researcher. They will be given an activation code and the participant then can download our app from the Google app store. Using the activation code, they will be able to register an account on the app. The researcher will observe (or remotely observe) the downloading and registering process, noting if/how much help the participant needs.

Before they can start using the app, a short tutorial on how to use the app will appear where participants view with at least one family member. Participants will have access to the study website where there will be written and video participant information sheet and link to download the app.

In this study, participants downloaded the App and then take it to the healthcare professional (remotely according to the social distancing regulation) – in which case the patient has a choice even though they are ‘encouraged’ to see their doctors. In reality, some of the information will be usable but the action plan will be remained blank (equivalent to a blank paper action plan which can be freely downloaded from patient websites (e.g. MyHealth Portal of the Ministry of Health, Malaysia)

During the first month, all usability data will be recorded such as the number of clicks, and time spent on the interface and frequency of login. Throughout this period, participants will be asked to provide online feedback via a platform (within the app) on the problems while using the app or improvements they wish to see. The feedbacks will be recognised by the unique codes used for log-ins. They can also feedback on the features that they like or any add-ons they wish to have. Participants will be able to use the app and contribute to the online feedback platform for three months. Health outcome assessment will be done on 0-month, 1-month and 3-month checkpoints (see section 3.3, table 4) and each call will be about 20 minutes.
4.3.5 Consent for reviewing app data usage

All participants will be given a non-identifiable ID to be able to use the App thus monitoring of the App use will be identifiable to any participants. We will only monitor the App’s use for research purposes.

All 35 participants will give consent (see appendix 3) to provide their app’s usage data for the research throughout the 3-month period (see table 4).

4.3.6 Recruitment for the qualitative study

For the qualitative study, we will purposively sample patients from the 35 participants of the feasibility study to achieve a maximum variation sample based on age, sex, ethnicity, and previous experience of using an action plan. The interview will take place at 0-month and 1-month checkpoints, purposively sampled participants will be invited for qualitative interviews. We will recruit until we have reached data saturation which we estimate will be about 15 patients.

We will also purposively recruit the 5 healthcare professionals (i.e., age, gender, ethnicity and roles (family medicine specialists and medical officers) who utilise the action plan at the 1-month checkpoint. The Universiti Putra Malaysia has a good relationship with local primary care practices and we anticipate a good response to our invitation.

Healthcare professionals in the Klang district have attended courses conducted by the RESPIRE team to improve knowledge on guideline-recommended asthma care such as providing asthma education, prescribing written asthma action plan and providing regular review. Previous research included the use of paper-based pictorial asthma action plans so all healthcare providers in the study area are familiar with the features in the mobile App such as asthma diary, medication list and pictorial asthma action plan which were similar with the paper-based version. In addition, we will conduct introductory sessions on the mobile App for all the recruited healthcare professionals so they can confidentially support the patients in using the mobile App. Due to the recent social distancing guideline, we will provide video-based introductory training about the App for healthcare professionals to view at own time. This video will be available in a public domain of the RESPIRE website and downloadable.
4.3.7 Consent for qualitative study

All 15 participants (see appendix 3/5) and 5 healthcare professionals (see appendix 4/8) will give consent to be interviewed (remotely) and for the interview to be audio-recorded.

Participants will give written consent by signing the consent form in hardcopy or online, the flexibility we will give the participants in-line with the social distancing measures after they understand about the study process and are willing to participate.

For the hardcopy version, participants may print and post it back to the researcher. For online form, participants may be given the option to complete the consent form online and email it back to the researcher.

4.3.8 Data collection

We chose a mixed-method observational research design for this study, so will collect quantitative and qualitative data. Quantitative data (from 35 participants) will measure quantifiable data such as occurrences (number of logins, usage of the app) and outcomes (health outcomes and practical technical outcomes). Qualitative data will help to understand views of stakeholders on the development of the intervention and to understand views and experiences, (e.g., of the 15 patients’ and 5 professionals’) on the usability of the intervention and feasibility of the delivery of the intervention.

4.3.8.1 Qualitative data

For the qualitative study, we will use in-depth interviews using a semi-structured topic guide. In-depth interviews are a highly effective method of collecting rich data,[37] and allow probing of topics brought up by participants, especially challenges in using technology and navigating it in daily life [37]. We will conduct the interview using online platform, in line with the social distancing measure outlined by the authority to ensure safety of participations during the pandemic period.

The interview will be conducted remotely through video-call, phone call or web-based call. If participants are not available for interview at a designated time, an alternative arrangement will be made through video-call, phone call or web-based call.
4.3.8.1.1 Topic guide: patients

We adopted three basic elements from COM-B (capability, opportunity and motivation) of the behaviour change wheel model. (See table 7 where we map the elements of COM-B to the questions of the topic guide). We will consult lay advisors to refine the topic guide.

Table 5 topic guide for patient

<table>
<thead>
<tr>
<th>COM-B Model</th>
<th>Initial interview</th>
<th>Follow-up interview</th>
<th>Research questions to be answered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Capability</td>
<td>• How would you describe your experience using the app so far? (registration, login) • What would you like to see in a pictorial asthma action plan app?</td>
<td>• How would you describe your experience using this mobile application to self-manage your asthma? (knowledge using an asthma action plan, technical capacity – features you like and don’t like)</td>
<td>• What are the facilitators and barriers (including technical factors) in using a pictorial asthma action plan via a mobile app to support asthma self-management among people with limited health literacy? • What are the features of the pictorial asthma action plan mobile app that patients would like to see and will continue to use on an app?</td>
</tr>
<tr>
<td>Motivation</td>
<td>• What made you decide to try this application? • What will make you use the application for the next few months?</td>
<td>• Are you still using the app? (why or why not?)</td>
<td>• What are the facilitators and barriers (including technical factors) in using a pictorial asthma action plan via a mobile app to support asthma self-management among people with limited health literacy?</td>
</tr>
<tr>
<td>Opportunity</td>
<td>• How would a pictorial asthma action plan help you to self-manage at home? • What do you think about the use of an app to store your asthma action plan?</td>
<td>• Has a pictorial asthma action plan helped you to self-manage at home, and if so, how? • What do you think about the use of an app to store the asthma action plan?</td>
<td>• How feasible is it to deliver a pictorial asthma action plan using a mobile application in Malaysia?</td>
</tr>
</tbody>
</table>
4.3.8.1.2 Initial interview (after app download)

After the patient has downloaded the app, during the first meeting, we will conduct the first in-depth interview (probably remotely). In this interview, we will explore initial motivation and expectations when using the intervention. The interview will be approximately 1 hour using a semi-structured topic guide (see Table 5).

4.3.8.1.3 Follow-up interview (at the 1-month checkpoint)

At 1-month, we will arrange for a follow-up interview which will be done in the clinic during one of the asthma review days. This will be followed by a remotely conducted, in-depth interview to explore the patients’ views and experiences when using the intervention through video-call, phone call or web-based call.

The interview will be approximately 1 hour using a semi-structured topic guide (see table 7) remotely.

At any point, if participants are faced with difficulty to attend the scheduled interviews, an alternative arrangement will be made.

4.3.8.1.4 Topic guide: Healthcare professional

We will interview at least five healthcare professionals after they have used the pictorial asthma action plan with at least one patient in their consultation at the 1-month checkpoint. This will be a remote in-depth interview using a semi-structured interview guide (see Table 8) which will be up to an hour.

Table 6 topic guide for healthcare professionals

<table>
<thead>
<tr>
<th>COM-B Model</th>
<th>Initial interview:</th>
</tr>
</thead>
</table>
| Capability  | • How would you describe your experience delivering the pictorial asthma action plan? (training? knowledge enhancement?)
|             | • What would you like to see in a pictorial asthma action plan app?                |
| Motivation  | • What would make you use or not use the pictorial asthma action plan app in your consultation? |
| Opportunity | • What do you think about healthcare professionals using a pictorial asthma action plan app to support self-manage at home? |
|             | • Physically, how ready is the system, at your setting, to support the intervention? |
4.3.8.1.5 Online feedback.
Throughout the 3-month feasibility study period, all patients are encouraged to be actively giving feedback on a platform within the app. They are free to comment specifically around the topic of the intervention and asthma/self-management in general. A researcher will have access to review the feedback but just as an observer. The feedback platform will be observed for another 2 months before it will be closed. Patients will be informed about the closure. The discussion posts will be used for data analysis.

4.3.8.2 Quantitative data

4.3.8.2.1 General data
Socio-demographic information and medical information will be extracted from the Klang Asthma Cohort Database. This includes age, gender, ethnicity and educational income, and medical information such as the duration of asthma, list of medications, triggers and unscheduled healthcare visits.

4.3.8.2.2 Feasibility outcomes
We will collect data on health and process outcomes (Table 4). Health outcomes include asthma control, number of severe attacks, steroid use, emergency department visits or hospitalisations. Process outcomes include attendance to follow-up, ownership of action plans and use of action plan in consultation. Ownership of action plans will be measured by asking the patient at baseline whether they currently have a plan. This is different ‘use of action plans’ which implies not only ownership of a plan but actually using it.

4.3.8.2.3 Usability testing
Usage patterns will be gathered through online software applications to collects data on how users physically interact with the application, e.g. no of logins, frequency of use, numbers of clicks on each link and time spent on the app.

4.3.9 Feasibility study: data analysis

Qualitative data synthesis and analysis
The interviews will be transcribed verbatim. The analysis of the interview data is an iterative process. Data analysis will start during data collection. The Malay Language is the official language in Malaysia. However, the interviews will be conducted in participants preferred spoken language (Malay, Mandarin, English). All researchers, HS, SSG and LPY are fluent in Malay and English languages and LPY is fluent in Mandarin. We will match participants’ preferred language with a researcher who can speak in similar languages. The transcripts will be transcribed verbatim and translated to
English. We will use back-to-back translation process to ensure the preservation of semantics and meaning of the content. The interviews, the transcriptions translation, identification of initial codes will be done in NVivo software version 11. Thematic analysis will be used to analyse the data in order to answer the objectives.

**Quantitative data analysis**
Using SPSS Statistics 23, descriptive analysis of the demographic characteristics of the participants, clinical history and usability data will be reported using:

1. Means and standard deviations (SD) or
2. Median and inter-quartile range (IQR) for continuous variables (depending on data distribution), and
3. Frequencies and percentages for categorical data.

**Mixed methods analysis and triangulation**
The advantages of using mixed methods are that it will provide a comprehensive dataset and understanding of the research questions. Data obtained from both the quantitative and qualitative components can enable triangulation and add rigour to the conclusions.

**4.4 Clinical outcomes and magnitude of change**

**Objective 3: To determine the baseline measurements and potential magnitude of change in health and process outcomes to inform a future trial**

The primary and secondary outcomes of interest are described in figure 9.

We will measure health outcomes as recommended by the European Respiratory Society/American Thoracic Society (ERS/ATS) Task Force report on asthma outcomes [28] including measures of asthma control and acute attacks at baseline, at the 1-month and 3-month checkpoint.

We will use the GINA’s asthma symptom control tools to assess asthma control [1], and self-reported future risks including the numbers of severe attacks, steroid courses, emergency department visits or hospitalisations which we will confirm with the participant’s health records. GINA’s asthma symptoms control tool is derived from expert consensus on symptoms that are pertinent to screen for asthma control (see appendix 1)[1]. It is a quick assessment to identify patients who need further evaluation and these classifications correlates with assessments made using other numeric versions of asthma control scores [38,39].