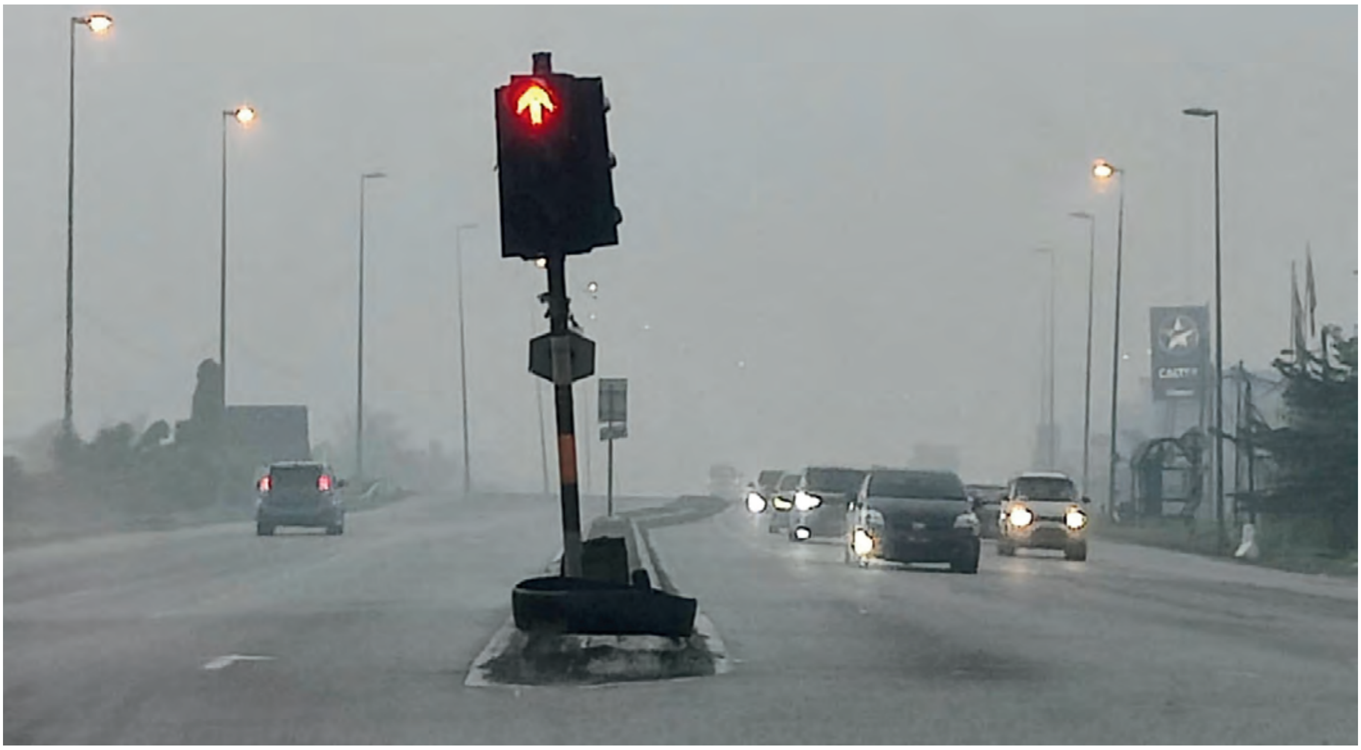
25 June 2025

Policy Brief

improving global
RESPIRE
respiratory health



LIVING WITH BREATHLESSNESS

PhotoVoice: A Participatory Exploration of Chronic Respiratory Disease in Malaysia

- This policy brief presents key insights from a Photovoice study involving people living with chronic respiratory diseases (CRDs) in Klang District, Selangor, Malaysia.
- Using photography and personal narratives, the study highlighted the everyday challenges of managing asthma, chronic obstructive pulmonary disease (COPD), and related conditions in low-resource settings.
- Findings were shared through a photo exhibition, where two participants stood beside their photographs and engaged with healthcare professionals (HCPs), whose reflections further enriched the interpretation of the photo narratives.
- Collaborative reflection and roundtable discussions informed the co-development of practical, system-level recommendations to strengthen CRDs care and support.

Research Approach

This Photovoice study was conducted between December 2023 and October 2024 with 14 participants living with CRDs in Klang District, Selangor. Participants included individuals living with asthma, COPD, and lung cancer.

Each participant received guided prompts for photo-taking and basic training on the ethics of photography. Over a period of 4 to 6 weeks, they documented their daily lives, capturing moments that reflected their challenges, routines, and aspirations. A total of 97 photographs were submitted.

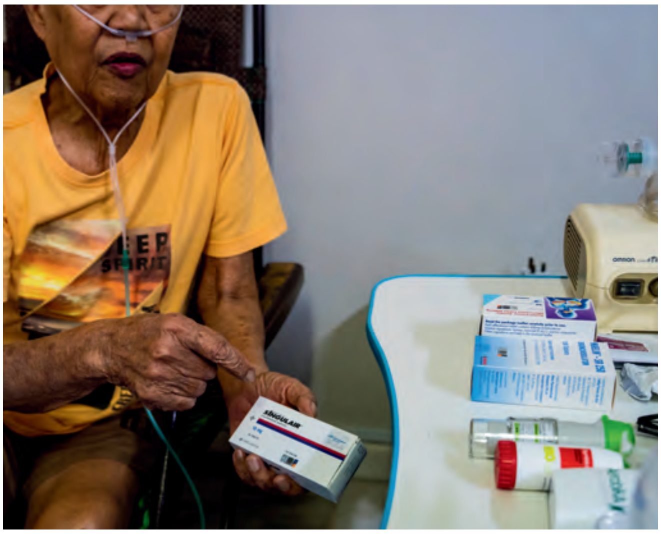
Individual interviews enabled participants to reflect on their photographs, generating personal narratives that were then thematically analysed.

Key Study Findings

The study reveals how people living with CRDs embrace breathlessness and manage it in ways that make sense to them. They navigate multi-level challenges and systemic inequities, cope with hope and resilience, and draw strength from family and friends.

i. Invisible Burdens Beyond Physical Symptoms

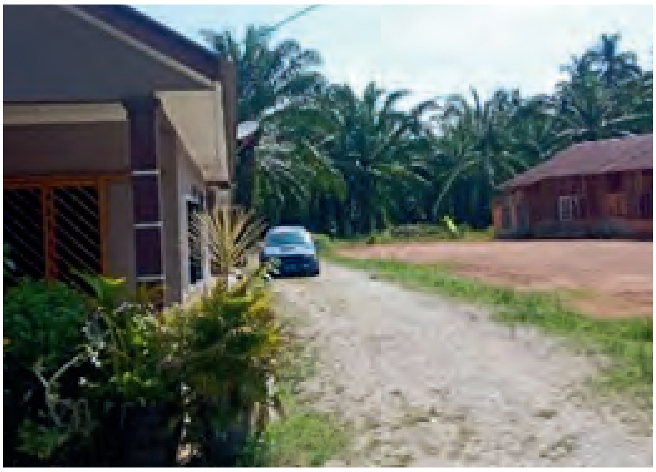
Beyond medical symptoms, many individuals experience fatigue, anxiety, and social isolation, burdens often worsened by systemic inequities.



"I never leave home without my inhaler. If I forget it, I turn back. It's my safety, my lifeline."

ii. Environmental Triggers That Disrupt Daily Life

Environmental triggers such as haze, rain, and dust further aggravate breathlessness and disrupt daily activities.



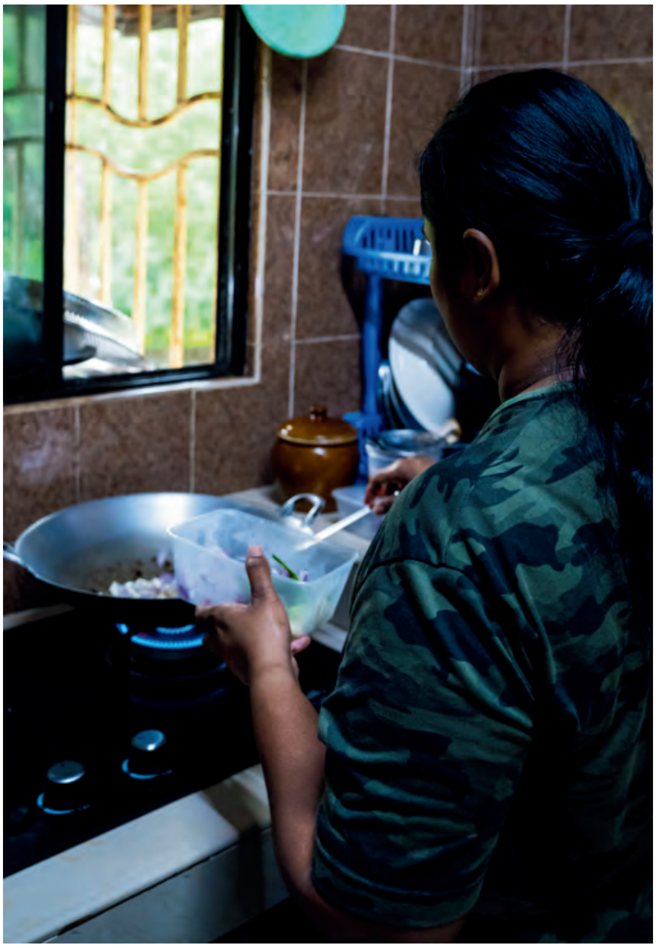
"It was hazy this morning but has cleared a bit. During haze, I shut the windows, stay indoors, and need my inhaler more. I often smell smoke at night, even if I don't see burning."

iii. Persistent Barriers to Healthcare Access

Barriers to healthcare include limited access to diagnostic tests and supportive equipment, medication quotas, transport costs, and long waiting times.

iv. The Role of Culture, Spirituality, and Gender Norms

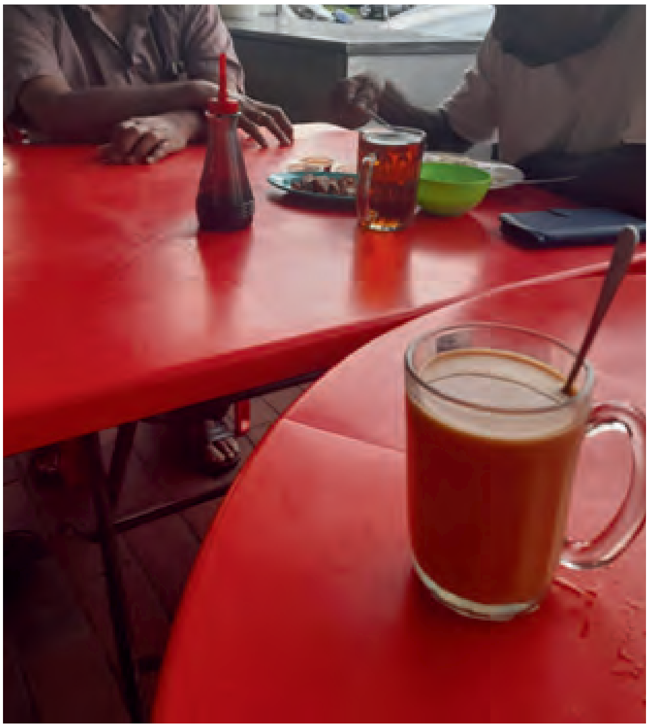
Cultural familiarity with traditional remedies and spirituality offers comfort and a sense of hope, often shaping how people respond to illness. However, socially prescribed roles, particularly for women, can be constraining and difficult to overcome.



“Even the smell of fried onions triggers my cough when I am cooking for my family. My chest tightens and I feel pain. Sometimes I have to stop everything.”

Policy Insights

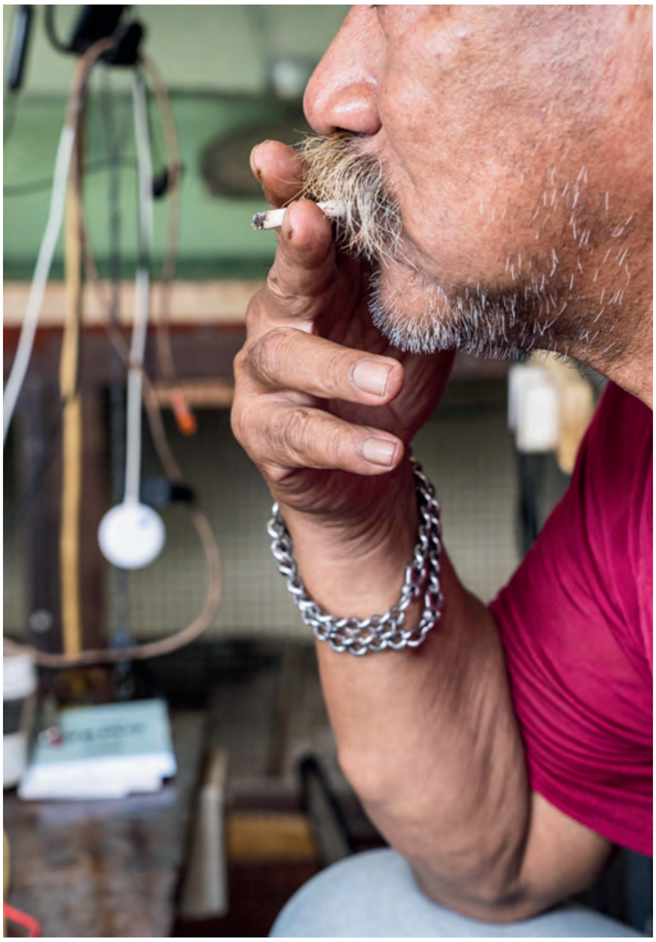
- Photovoice amplifies patient voices and offers a unique lens into how people living with CRDs manage breathlessness amid cultural norms, environmental hazards, and systemic barriers.
- Traditional clinical encounters often overlook the emotional toll of CRD. Participants shared experiences of fear, fatigue, isolation, and gendered responsibilities, all of which influence care-seeking behaviours and medication use.



“Spending time with friends helps me forget my illness. They support me when I’m down and remind me I’m not alone.”

- Exposure to second-hand smoke in public spaces and eateries remains a serious challenge, highlighting the need for stricter enforcement of smoke-free policies.

- Traditional remedies and spiritual practices provide comfort and reflect cultural familiarity, highlighting the importance of culturally sensitive care.
- Community-based solutions, such as drive-thru pharmacies and medication delivery, have improved access and adherence, and should be considered for broader implementation.
- Patient–provider dialogue through participatory methods strengthens trust and can inform more inclusive and responsive health systems.
- Visual narratives can enrich clinical training, health promotion, and policy advocacy by deepening understanding of lived experiences in low-resource settings.



“I didn’t realise cigarettes had damaged my lungs until I was hospitalised. I quit right after, but the damage is done.”

Recommended Actionable Policy

- Incorporate patient stories into CRD awareness campaigns, clinic-based education, and healthcare training.
- Expand access to diagnostic tools, essential medications, and community-based support services.
- Strengthen inter-ministerial coordination to address CRD-related issues in air quality, education, and healthcare delivery.
- Pilot participatory approaches, such as Photovoice, within national health programmes to enhance engagement and responsiveness.

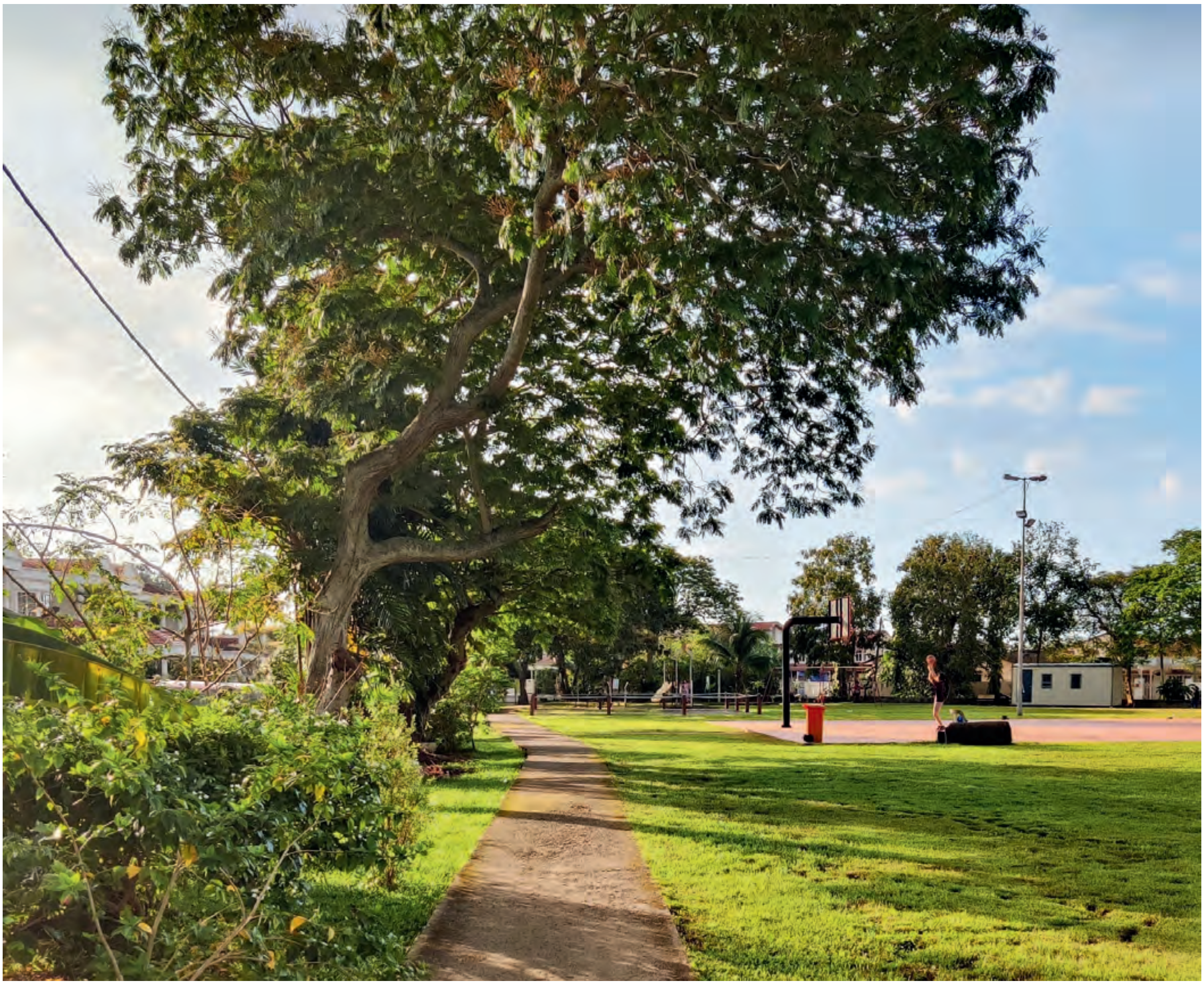
AUTHORS AND AFFILIATIONS

Hani Salim[1], Jayakayatri Jeevajothi Nathan[2], Ai Theng Cheong[1], Norita Hussein[2], Nik Sherina Hanafi[2], Bee Kiau Ho[3], Salbiah Mohamad Isa[3], Noriah Ismail[4], Fatin-Syazwani Abd-Malek[2], Nursyuhada Sukri[2], Kent Ka Kian Goh[2], Sheron Sir Loon Goh[5], Melissa Ali[3], Eman Nazlan[2], Ee Ming Khoo[2]

[1] Department of Family Medicine, Faculty of Medicine and Health Sciences, Universiti Putra Malaysia, Selangor
[2] Department of Primary Care Medicine, Faculty of Medicine, Universiti Malaya, Wilayah Persekutuan Kuala Lumpur
[3] Bandar Botanic Health Clinic, Klang, Selangor
[4] Klang Health District Office, Ministry of Health Malaysia, Selangor
[5] Department of Clinical Pharmacy and Pharmacy Practice, Faculty of Pharmacy, Universiti Malaya, Wilayah Persekutuan Kuala Lumpur

ACKNOWLEDGEMENT

This policy brief was developed with contributions from healthcare professionals and community participants involved in the Photovoice study, and designed with input from the RESPIRE Malaysia research team. The content of the policy brief is grounded in fieldwork conducted in 2024 across the Klang District, Selangor, and a roundtable discussion with stakeholders.



This research was funded by the UK National Institute for Health Research (NIHR) (Global Health Research Unit on Respiratory Health (RESPIRE); 16/136/109) using UK aid from the UK Government. The views expressed are those of the author(s) and not necessarily those of the NIHR or the UK Government. The RESPIRE collaboration comprises the UK Grant holders, Partners, and research teams as listed on the RESPIRE website (www.ed.ac.uk/usher/respire).