

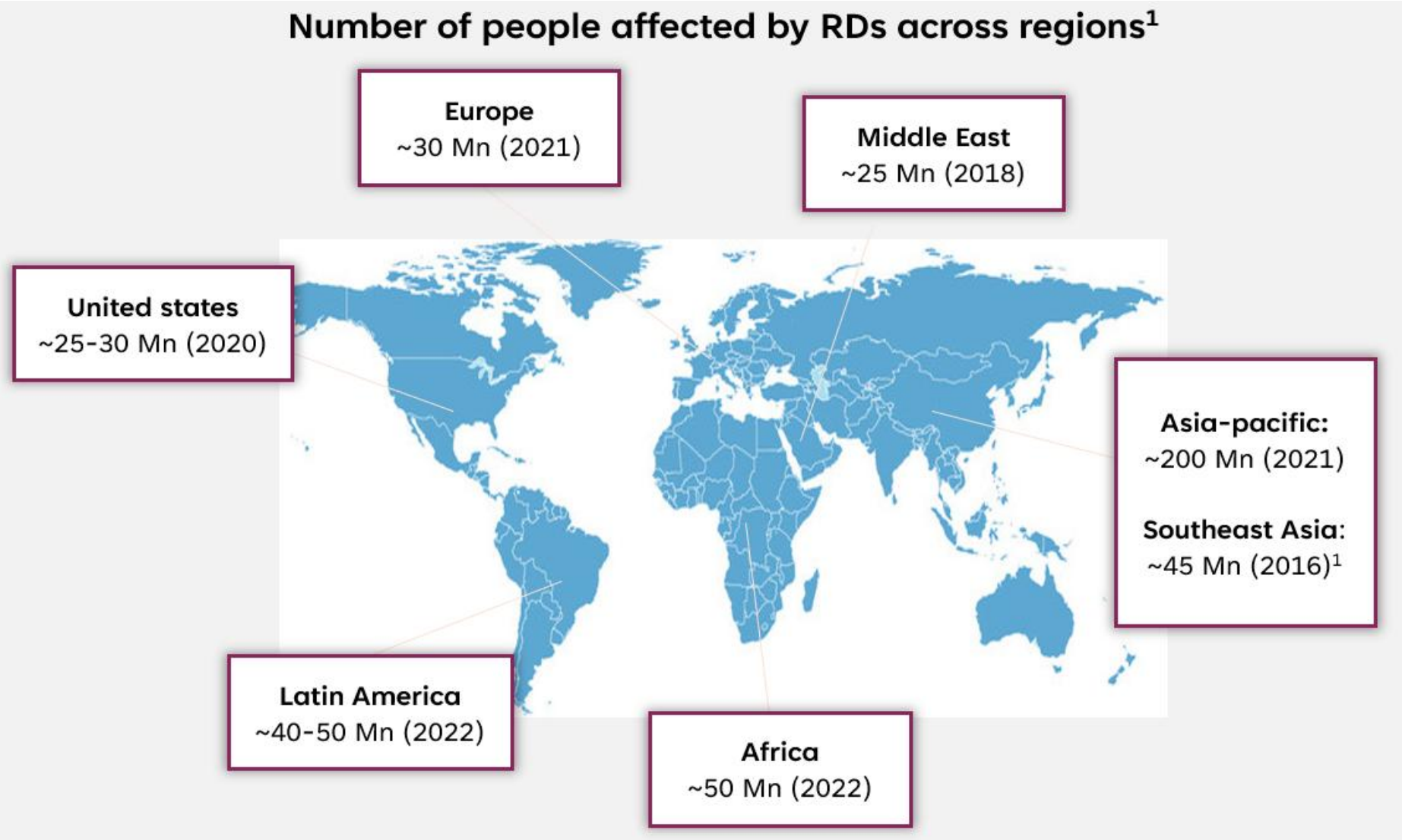
Advancing Rare Disease External Engagement in Southeast Asia: Stakeholder Mapping and Policy Assessment Across Six Countries

AUTHORS

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Introduction

Rare diseases collectively affect **over 300 million people worldwide**, yet remain **under-recognized and under-prioritized**, particularly in **low- and middle-income countries**. Across **Southeast Asia**, patients often experience **delayed diagnosis, fragmented care, and limited access** to essential treatments. The diversity of national health systems, coupled with **inconsistent policies** and **weak advocacy networks**, further amplifies inequities in care.



In 2025, the **World Health Organization (WHO)** Resolution on rare diseases renewed the global call to strengthen **policy frameworks, patient engagement, and research collaboration**. Responding to this momentum, this study assessed six Southeast Asian countries to **map key stakeholders**, identify **systemic barriers**, and outline **strategic priorities** for advancing **patient-centered rare disease care**. By integrating **policy analysis** with **stakeholder perspectives**, this research provides evidence-based insights to inform future **regional collaboration**, promote **equitable access**, and drive the development of sustainable **national rare disease strategies**.

This assessment covered six Southeast Asian countries, **Malaysia, Singapore, Thailand, the Philippines, Vietnam, and Indonesia**, to evaluate rare disease policy, funding, diagnostics, advocacy, and stakeholder engagement. The study analyzed national frameworks and stakeholder perspectives to identify gaps and opportunities for regional alignment and capacity building.

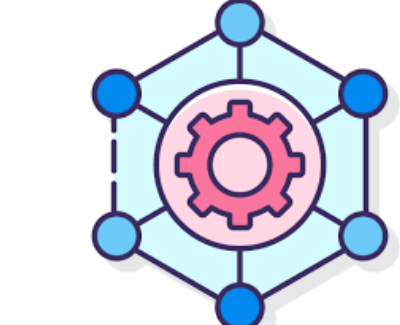
Objective

The study aimed to **assess the rare disease policy landscape** across **six Southeast Asian countries** to identify existing **gaps, barriers, and opportunities** in access, funding, and governance. It sought to **map key stakeholders**, evaluate **national frameworks** across five domains, **policy, funding, advocacy, diagnostics, and engagement**, and propose **strategic priorities** to strengthen **patient-centered care** and policy alignment.

Building on the momentum of the **2025 WHO Resolution on Rare Diseases**, this research also aimed to **benchmark regional practices** against **global standards**, highlighting actionable pathways for governments, advocacy groups, and industry partners. By combining **policy assessment** with **stakeholder insights**, the study provides a foundation for **collaborative policy reform, capacity building, and equitable access** to diagnosis, treatment, and long-term support for rare disease patients across Southeast Asia.

Methodology

This study employed a structured, five-phase qualitative framework to systematically evaluate the rare disease landscape across six Southeast Asian countries. Through the integration of policy analysis, stakeholder mapping, and expert consultations, the study generated robust, evidence-informed insights into existing policy frameworks, implementation gaps, and opportunities for advancing equitable rare disease care in the region.



Typology Development

Developed a structured **assessment framework** covering five key domains – **policy, funding, advocacy, diagnostics, and engagement**.



Desk Research

Reviewed **national health policies, publications, and grey literature** to identify trends and gaps.



Key Informant Interviews

Conducted **semi-structured interviews** with policymakers, clinicians, patient advocates, and NGOs.



Cross-country Comparison

Aligned findings with the **WHO 2025 Resolution** and global benchmarks to shape **policy recommendations**.



Evidence Synthesis







Aligned findings with the **WHO 2025 Resolution** and global benchmarks to shape **policy recommendations**.

Results

The study identified **critical gaps and opportunities** in rare disease care across six Southeast Asian countries. Despite ongoing initiatives, patients continue to face **delayed diagnosis, limited access to treatments, fragmented care, and inconsistent funding**. Key differences exist in **national policies, reimbursement frameworks, and stakeholder engagement**, highlighting the need for **tailored policy interventions**. Strengthening **national registries, regulatory pathways, funding mechanisms, and patient advocacy networks** emerged as priority actions to improve **equitable access, early diagnosis, and coordinated care** across the region.

These findings emphasize the importance of **regional collaboration and multi-stakeholder engagement**. By leveraging **global best practices** and fostering **evidence-informed policies**, Southeast Asian countries can enhance **rare disease awareness, streamline care pathways**, and ensure **sustainable access to treatments**.

Results

Country	Key Insights
 Malaysia	Limited rare disease registry; misdiagnosis; fragmented policy frameworks
 Singapore	High treatment costs; lack of cohesive national action plan
 Thailand	No compassionate use program; limited coverage of orphan drugs
 Philippines	Rare Disease Medicines Access Program limited; no national registry
 Vietnam	No official rare disease definition; inadequate diagnostic guidelines
 Indonesia	No orphan drug legislation; lack of national action plan

Lessons Learnt

This multi-country assessment highlights the need for stronger regional alignment and sustainable approaches to rare disease care in Southeast Asia. Policymakers, patient groups, and healthcare partners must collaborate to close persistent gaps in diagnosis, funding, and coordinated care. The findings emphasize on actionable recommendations to advance equitable access and patient-centered policy reform.

Strengthen National Frameworks

Establish comprehensive rare disease strategies & standardized definitions

Facilitate Patient Engagement & Stakeholder Collaboration

Strengthen multi-stakeholder platforms, ensure patient voices guide decisions

Improve Funding Mechanisms & Access

Implement risk-sharing models, ensure equitable reimbursement, increase funding

Enhance Access to Genetic Testing & Counseling

Expand diagnostic capacity, promote early diagnosis, integrate genetic services

Knowledge Exchange & Capacity Building

Develop training programs, share best practices, foster regional collaboration