POLICY BRIEF

Strategies to address the high incidence of leprosy among the Penan in rural Baram, Miri, Sarawak

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Executive summary

The Penan community in Sarawak continues to experience a disproportionately high burden of leprosy**,** accounting for nearly 50% of all reported cases in the state**.** Notably, almost two-thirds of these cases originate from the Upper Baram region**.** To better understand and address this issue, three phases of research have been conducted, focusing on identifying disease patterns, exploring stakeholder views and pilot testing leprosy awareness materials developed in the Penan language.

The findings revealed that the persistence of leprosy among the Penan is the result of multiple interrelated factors—including environmental conditions, socio-cultural beliefs, geographic isolation, and limitations within the healthcare delivery system**.** Effective elimination of leprosy in the Penan community requires targeted interventions that directly address these root challenges**.**

A comprehensive and sustainable response must include:

- **Community-led** initiatives that foster trust and ownership,
- **Culturally** and **linguistically** appropriate health education tailored to the Penan context,
- Conducting regular active **case detection** and **contact tracing**,
- Strengthening of rural **healthcare infrastructure** and **outreach services**, and
- **Collaborative partnerships** among government agencies, NGOs, local leaders, and researchers.

Introduction

The road to the last mile in leprosy elimination for Malaysia

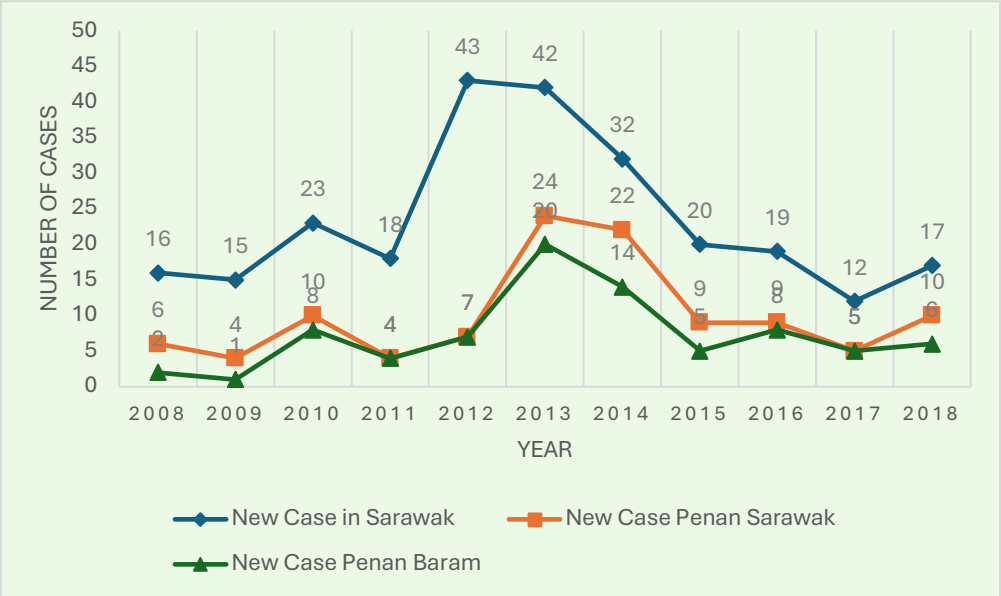
Leprosy, although eliminated as a public health problem globally in 2000, remains a significant issue particularly in remote and marginalised communities. Malaysia achieved national leprosy elimination in 1994, with Sarawak at state level following suit in 1996. However, **the Penan population in the Baram district of Sarawak continues to experience high leprosy incidence above recommended WHO elimination targets**, with an annual prevalence rate of 5.5 per 10,000 population from 2000 to 2013 (Box 1).

Despite efforts to control the disease, underlying factors contributing to the high incidence among the Penan community are not fully understood. A group of researchers comprising university, health and administrative team members have conducted health programs and **research into the issue since 2013,** working in Upper Baram where leprosy continues to heavily affect isolated, rural Penan communities. **This policy paper outlines our research findings and policy recommendations that follow.**

Box 1: Annual trend of leprosy in Sarawak with Penan-specific cases 2008-2018[1]

The figure below shows that approximately half of the total cases in Sarawak in 10-year period are from the Penan, with Penan in the Baram region contributing between 25-100% of the Penan cases every year. This shows that the disease is concentrated in villages in this region.

A large increase in cases in 2012-2013 was due to the initiation of a government program to actively screen for leprosy by going door-to-door in villages with known leprosy, highlighting the impact of targeted policies and interventions.



Overview of the research or problem

Research approach

The study adopted a sequential combination of quantitative leprosy records analysis (Phase 1), followed by interviews with key stakeholders to understand the reasons for high leprosy incidence among the Penan (Phase 2) and finally a Penan-language leprosy awareness campaign in the most affected villages (Phase 3).

For **Phase 1,** a 10-year retrospective analysis (2008–2018) compared **leprosy incidence and prevalence among Penans in Baram to Sarawak state-level data**, and a 5-year review (2013–2018) examined the **demographic and clinical profiles of leprosy cases** among Penans specifically in the Baram region.

In **Phase 2**, a total of **37 in-depth interviews were conducted from January to May 2022** with healthcare professionals (n=15), leprosy patients (n=12), community leaders (n=5), village health promoters (n=3), and patient caregivers (n=2) from villages with known leprosy cases including Long Sait, Long Lamai, and Long Beruang. Interviews were used to explore leprosy from healthcare providers' and Penan's perspectives, focusing on lifestyle, culture, beliefs, and factors affecting high incidence of leprosy and challenges in leprosy management.

Finally, in **Phase 3**, to address the lack of awareness found in the Phase 2, a study was conducted to **develop and evaluate Penan-language leprosy awareness materials**. A multidisciplinary team comprising medical doctors, psychologists, linguists and a Penan officer worked together to develop the materials. These materials were evaluated with Penan community leaders and members, and healthcare providers in Long Banga, Long Lamai and Long Beruang (Figure 1 and 2).

Figure 1: Blood pressure and blood sugar screening at Long Beruang (May 2025)

Figure 2: Checking for signs of leprosy at Long Lamai (May 2025)

Research results

The review of leprosy records, covering the years from 2008 to 2018, found that **about half (42.8%) of the 257 new leprosy cases reported in Sarawak were from the Penan community, with Baram district accounting for 72.7% of Penan cases.** The prevalence among the Penan population consistently exceeded the World Health Organization's elimination threshold (defined as prevalence of less than 1 per 10 000 population), ranging from 2.08 to 35.5 per 10,000 population. The **clinical profile** indicated a higher incidence in **males** (63%, n=29/46), with a mean age at diagnosis of **38.4 years**. Most cases (76.1%, n=35/46) were detected via **active case detection**. 43.2% (n=19/44) of cases **presented with grade 1 and 2** disabilities at diagnosis, and 85% (n=34/40) successfully **completed treatment**. The mean duration of symptoms prior to diagnosis was 7.9 (SD±4.9) months, while the average time to initiate treatment following clinical diagnosis was 36.6 (SD±35.4) days. Villages in Upper Baram with the highest incidence of leprosy were Long Beruang (n=16/46), Long Sait (n=14/46) and Long Lamai (n=9/46).

Analysis of the interviews identified several factors contributing to the high incidence. The first were **healthcare system challenges**, such as limited number of healthcare workers and resources for patient testing in the diagnostic process, infrequent active case detection, and access barriers due to geographical isolation and transportation issues which hindered effective management. **Cultural factors,** such as reliance on traditional medicine and fear of diagnostic procedures, further delayed diagnosis and treatment. **Other factors** included lack of awareness, family-level transmission, migration between villages, nutritional deficiencies, overcrowded living conditions and zoonotic risks.

Finally, based on the epidemiological and qualitative study findings, **Penan-language leprosy awareness posters** were developed and evaluated with healthcare professionals working in the Baram region (n=5), and Penan community members, including village heads and village health promoters (n=12) (see Figure 3). **Four buntings and 200 posters were also distributed to the Long Banga health clinic (Klinik Kesihatan Long Banga) and the communities**. Analysis of the interviews indicated that the use of Penan language was well received by both Penan community leaders and members, and by healthcare workers. Incorporating images of real people helped convey the reality of the disease and enhanced the familiarity and trustworthiness of the materials. The real-life pictures of the clinical signs including skin lesions and complications, such as the deformities in the hands and feet, were perceived to be an important element in the posters.

Besides the posters, **a community health talk on leprosy awareness** was delivered at Long Beruang on 16th May 2025 in conjunction with a community empowerment program organised at the Rural Service Center Long Beruang using standard Malay language material from Dr Maurice Utap followed by Penan language materials explanation in Penan by Dr Benard Upieh. **The participants asked more questions after the Penan language materials were delivered**, and Dr Maurice observed that this was different from his previous talks on leprosy in Penan villages (Figures 4 and 5).

Figure 3: Penan language posters- Symptoms of Leprosy (L), Treatment of Leprosy (R)

Figure 4: Benard Upieh and Dr Maurice Utap during leprosy Q&A with village heads at Long Beruang (May 2025)

Figure 5: Distributing bunting and posters on leprosy to village pastor at Long Lamai

Examination of the findings

The geographical isolation of the Penan in Upper Baram creates a multi-layered system of barriers that prohibits early detection and treatment of leprosy, allowing the disease to spread in communities. This isolation, coupled with a lack of awareness of the communities about the disease itself, points towards some key policy recommendations that should be considered.

The findings show that active case detection worked well for identifying new cases in the community. The Penan are not averse to being treated, as suggested by the relatively high treatment completion rate, indicating that with effective case detection, it is possible to treat the disease and stop the chain of transmission in the community.

The close-knit community needs to be considered as an important lever when developing strategies to address leprosy, as indicated by the village hotspots and the transmission between families and villages. This indicates that targeted awareness campaigns need to be delivered using a community-led approach.

Based on the experience in developing and disseminating Penan-language posters on the symptoms and treatment of leprosy, we noticed that the Penan could understand the information about the disease and trusted the information provided as it was more tailored to their culture. They were more interactive during health promotion talks compared to previous experiences with standard materials in Malay language (Bahasa Melayu).

Conclusion: Policy recommendations and implications

The findings underscore the multi-faceted nature of leprosy persistence in the Penan community, shaped by environmental, social, cultural, and healthcare system challenges. Addressing these requires a comprehensive approach that includes community-led approaches, culturally and linguistically appropriate health education, strengthened active case detection, improved healthcare infrastructure, and robust collaborative partnerships. These five recommendations are described below.

1. Adopting community-led approaches

Community-driven approaches represent strategic interventions that **leverage the collective agency of community members to address the re-emergence of leprosy**, a disease that was previously considered eradicated. Current epidemiological data indicate a resurgence of cases within the Penan population in Upper Baram, necessitating a two-pronged approach. Firstly, it is crucial to **disseminate comprehensive information** regarding the continued presence of leprosy within this community. Secondly, efforts must be focused on **encouraging community participation in health screenings and ongoing monitoring at local clinics**. These efforts include the sustained support and training of new and existing village health promoters ('wakil Kesihatan kampung') to spearhead awareness campaigns, facilitate active case detection in collaboration with healthcare providers, and trace individuals who have defaulted on treatment. The engagement of community leaders, such as Pemanca, Penghulu, Ketua Kampung, and pastors, is paramount in fostering trust within the community towards the healthcare system and promoting receptiveness to treatment protocols**.**

2. Developing culturally and linguistically appropriate health education

Developing Penan-specific education materials should involve several key stakeholders as mentioned in the Research Approach above. From our experience, a multi-stakeholder team was important in ensuring content was accurate and up-to-date, materials designed were culturally sensitive and adhered to adult communication theory (such as the use of real-life people and pictures of symptoms), and native Penan speakers helped to translate the materials accurately. Due to the low educational levels, **low-health literacy approaches using simpler language and more pictures should be adopted.** Although the Penan did not have any specific cultural recommendations to be incorporated into materials, **including known faces of healthcare workers and actual pictures of leprosy from local settings** helped lend credibility to the health information. This could increase trust in the content and motivate Penan to act on the recommendations. Other similar strategies using real life people are testimonies from Penan who have recovered or admonitions from village leaders to seek treatment for symptoms.

3. Enhance active case detection and surveillance

Although costly, it is important to prioritize **regular and systematic active case detection (ACD) in high-risk areas.** For example, conducting an annual ACD program for Upper Baram with 6 monthly ACD for villages with high incidence timed to avoid planting or harvest times when villagers are away in the fields could help to identify cases earlier and prevent further spread. This could include door-to-door surveillance or community screening initiatives. A more **robust system or template of tracking treatment**

completion and contact tracing should be implemented to ensure the disease is contained when cases are detected. **Collaboration between primary care providers and public health officers** should be tightened to ensure effective contact tracing and treatment completion. For instance, establishing **a digital registry for leprosy** can help coordinate efforts between health clinics, public health personnel and flying doctor services to improve contact tracing and follow-up. **Training of healthcare providers in primary care and public health should be improved** especially with a high turnover rate of health providers in rural villages. Strategies should include standardising and expanding access to training in leprosy knowledge and leprosy surveillance system through eLearning modules and allocating funding to train healthcare workers on improving diagnostic skills i.e. slit skin smear test.

4. Improve healthcare access and delivery

Geographical isolation is the main challenge of healthcare access for leprosy diagnosis and treatment. Resources should be allocated to **provide transportation subsidies and logistical support** to reduce financial and physical barriers to accessing healthcare services. In view of the availability of good internet access in most of the villages like Long Lamai and Long Beruang (through the Sarawak Linking Urban, Rural, and Nation initiative. Source: https://saluran.my/), strategies should include the **use of mobile health and telemedicine to ease tracking of patients and contact,** communication with health providers, disease monitoring and health education dissemination. To prevent delay in initiating treatment for leprosy, **point-of-care testing** (particularly for full blood count, renal profile, and liver function test), should be made available for use in rural locations.

5. Enhance collaborative partnerships

Given the complex nature of leprosy transmission and control in Penan communities, it is essential to **strengthen the partnerships between primary care, public health, other government agencies** (such as the Sarawak Economic Planning Unit), non-governmental organizations (such as The Malaysian Leprosy Relief Association (MALRA)), local community organizations and religious bodies (such as the church). Each agency has a unique role to provide additional resources, expertise, and outreach efforts to help with active case detection and access to healthcare services. Primary care providers and public health officers, who know both the patients and agencies, should actively coordinate the care and resources between different agencies. Ad-hoc arrangements could delay coordination and a joint committee led by the Ministry of Health could be established to tackle this problem.

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Acknowledgement

Funding for work related to the preparation of this report was received from Ungku Aziz Center for Development Studies, Universiti Malaya (Grant number: UMG005-2024UAC).

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