

## Community Participation and Volunteering Among Orang Asli During The Measles Outbreaks In Kelantan: An Ethnography Perspective

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### Abstract

Low health standards and access to healthcare services for indigenous Malaysians continue to be significant challenges. Poverty, malnutrition, poor hygiene, environmental contamination, and the prevalence of infections all contribute to poor health. This study examines the complexities of culture and its interaction with various intersecting influences on promoting community participation in disease prevention and control behaviour by providing a narrative experience of Orang Asli accessing health care in Kelantan. A focused ethnographic study was carried out to understand and describe the community involvement and participation among the Bateq Tribes in Gua Musang, Kelantan in relation to prevent measles disease from spreading in the community. This study will also look at health behaviours and other cultural phenomena related to the problem. We recruited 26 participants (17 males and 9 females) ranging in age from 18 to 60 years old, and in-depth semi-structured interviews were conducted to investigate the participants' experiences living in a semi-nomadic culture. Data analysis was informed and guided by Roper and Shapira's framework for ethnographic analysis. Four themes emerged from an in-depth understanding of indigenous peoples' experiences in the larger sociocultural context in which they lived. Data analysis revealed that community involvement, competing interests among community and stakeholders, community decision making and participation, participation in prevention and control of disease all contribute to the factors and challenges that drive the indigenous community in preventing and disease control behaviour. The high prevalence of chronic disease and risk behaviours among indigenous peoples has resulted from the interaction of numerous underlying causes, including population group differences and a variety of ecological, cultural, and social determinants of health with varying degrees of impact. There

is an urgent need to focus on general health and specific health conditions, wellness, cultural practises, healthcare service seeking, healthcare provider relationships, and self-care optimization. These findings may benefit future efforts to improve healthcare access and reduce disease burden, allowing for the development of more effective strategies, programmes, and policies.

**Keywords:** Community Participation and Involvement, Orang Asli, Disease Control and Prevention, Ethnography

### **Introduction**

Globally, the Orang Asli number about 5% of the population and make up 15% of the world's poor. The Orang Asli is ethnically different and there are usually minority groups that are interpreted as the owners of the territory before the invasion or conquest as a nation state (Greenwood, 2015). In most areas, their life expectancy is lower and is often associated with higher levels of food insecurity, chronic diseases including diabetes and reported higher levels of violence and injury, including self-harm and suicide. Many Indigenous communities in the world have disappeared because they have lost the right to access and use land that has been taken over for development purposes. Discrimination and poverty also cause the delivery of public services, health and education facilities cannot be delivered fairly. This disparity occurs in many countries around the world including in developed countries that have the best wealth and health expertise. To reduce human rights violations, discrimination, and marginalization of the Orang Asli community in the world, the United Nations has set international standards that aim to recognize the achievements and contributions of the Orang Asli in the world to support the promotion and protection of their rights (Health Poverty Action, 2018).

The complexities surrounding healthcare practices and disease treatment behaviour among the Orang Asli community in Malaysia are indeed multifaceted and require a nuanced understanding. In summary, the complexities surrounding healthcare practices and disease treatment behaviour among the Orang Asli require a holistic and culturally sensitive approach that addresses both the immediate barriers to healthcare access and the underlying social, economic, and cultural determinants of health within the community. It is complicated and takes rigorous investigation to address this issue how Orang Asli health care practises and disease treatment behaviour differ from other populations. In Malaysia's Orang Asli group, treatment-seeking behaviour has been found to be impacted by differences in socioeconomic level, geographic variables, culture, beliefs, experiences, and ways of life. Even though the government consistently prioritises Orang Asli individuals' access to healthcare, the state of the health system still seems underwhelming, and the incidence of diseases seems to be rising annually (KKM, 2019). According to the United Nations (2015) and Thummapol et al. (2020), barriers to obtaining therapy to attain optimal health include geographic issues, degree of communication, faith in contemporary medicine, and narrowness of life.

Studies conducted in Asian countries have previously found that there is a gap in the facilities for obtaining treatment between the Orang Asli and non-Orang Asli populations where these people are often neglected (Dhir et al., 2015; United Nation, 2010). Literature review shows that there are significant differences in health access and availability of services among Indigenous women in Asia compared to non-Indigenous people (Thummapol et al., 2020; Dang, 2012). In India, Orang Asli women are given low priority and are often neglected by the government from getting sexual and reproductive health services and are given less care when they seek treatment compared to the United States or Australia (United Nation, 2015).

The imbalance of health services is also seen to exist in the Orang Asli group in Thailand where, the Orang Asli who live in rural areas have limited access to health care or none at all and they tend to get health services through mobile health teams that bring services into Orang settlements original This inequality of access to treatment has a negative impact on health care between Orang Asli and non-Orang Asli groups (Dhir, 2015; United Nation, 2010) resulting in many Orang Asli women and children being affected by diseases that should be preventable such as cervical cancer , HIV/AIDS, and other diseases (Kritpetcharat et al., 2012). In addition, they also experience various forms of discrimination and often have difficulty obtaining health services due to identity differences and gender inequality (Lutvey et al., 2014). At the global level such as in Bangladesh, (Chowdhury et al., 2017), Canada (Denison et al., 2014), Guatemala (Schooley et al., 2009), India (Shah et al., 2011), and in Vietnam (Dang, 2012) shows the lack of access to health by the Orang Asli community has affected the health status of the Orang Asli community with a high disease burden.

In Malaysia, reports of disease cases are also increasing every year even though the government always places emphasis on improving the quality of health for the Orang Asli (KKM, 2019). Compared to the population of other races, the level of health of the Orang Asli community was found to be very low. They have a lower life expectancy rate with an average age of 53 years compared to the non-Orang Asli community of 74.5 years (Department of National Statistics 2019), and a high infant mortality rate of 51.7 people per 1000 births compared to the national infant mortality rate of 8.9 people (Masron T, 2013). The report also shows an increase in cases of communicable and non-communicable diseases among the Orang Asli community.

### **Materials and Methods**

Data were collected from 11 November 2019 to December 2019 in the province of Gua Musang, Kelantan Malaysia, where there was a high prevalence of infectious diseases, particularly measles, in this region compared to other parts of the country. The measles outbreak in May 2019 that claimed the lives of 16 Bateq villagers in Kuala Koh, Kelantan's Gua Musang district, had devastating consequences for the community. Two years have passed since this tragic event, and the repercussions are still felt by the affected families and the broader Bateq community. Measles is a highly contagious viral disease caused by the measles virus (MeV).

### **Study Area**

An ethnographic study was conducted in a village with the highest reported incidence of measles disease in the province. The village, Kuala Koh, located approximately 95 kilometres in opposite directions from the provincial town centre (known as Gua Musang) and around 184 kilometres from the Capital, Kota Bharu. Most villagers are poor farmers, collecting forest products, harvesting wild honey, collecting dammar and gaharu. Environmental conditions in the villages are conducive to measles transmission. It spreads through respiratory droplets when an infected person coughs, sneezes, or talks. Measles can lead to various complications, especially in young children and individuals with weakened immune systems. These complications can include ear infections, pneumonia, encephalitis (brain inflammation), and even death in severe cases.

**Data Collection**

Data collection methods included key informant interviews, focus group discussions, in-depth interviews, and ongoing participant observation, as well as structured observations and environmental surveys. Key informant interviews were conducted with all village health volunteers about villagers' awareness and perceptions about measles disease, and their participation in prevention, control, and development activities. Three focus group discussions were conducted with mothers or other family caretakers of their family, to gain insight into their understanding of measles disease and their involvement in prevention and control measures. In-depth interviews were then conducted with 9 men and 3 women who is of their family had been infected in the past year or during the research period, including about their participation in measles prevention and control activities and their views about control programme activities. Women were also asked about changes in their village, and so could speak of issues about which they may have been reticent publicly. These data were complemented by questionnaires with 14 other participants, representing 9% of households where their family had no history of measles, on their participation in prevention and control activities. One focussed group discussion was conducted with health staff at health centres, (Clinic Kesihatan Aring 1) provincial and national levels on community participation. All data were entered into computer, codes were developed, and the data were analysed thematically. Ethics approval to conduct this research study was granted by the National Medical Research Registration (NMRR 19-3775-52078) Medical Research Ethics Committee of National Institutes of Health Malaysia. All potential participants were provided with plain language Participation Information Sheets in Malays (Malaysia's national language), and the project was explained to them verbally. Consent to participate was verbal, since the collection of signatures held negative connotations for most people.

**Results****Community involvement among the villagers in Kuala Koh, Gua Musang**

Finding from this study show that, the indigenous people of Malaysia, play a significant role in measles control efforts within their communities. Their involvement is crucial for culturally sensitive and community-driven approaches to preventing and managing measles outbreaks. Respondents' perspective show that a more commitment of indigenous people is needed in measles control. Orang Asli community members can serve as health educators within their communities. They can help raise awareness about measles, its symptoms, transmission, and the importance of vaccination. They can convey information in culturally appropriate ways and local languages to ensure better understanding. Orang Asli leaders and community members can actively promote measles vaccination campaigns within their villages. They can encourage community members to get vaccinated, dispel myths or misconceptions about vaccines, and address vaccine hesitancy. Orang Asli leaders also can mobilize community members to participate in vaccination drives and other measles prevention activities. Their influence and trust within the community can encourage higher vaccination rates. Orang Asli communities have unique cultural practices and beliefs. They can provide valuable insights into cultural nuances that may affect healthcare delivery. Health programs can be tailored to respect these cultural sensitivities. Orang Asli leaders can act as intermediaries between healthcare authorities and the community. They can help facilitate communication, build trust, and ensure that healthcare services are accessible and acceptable to the community. Orang Asli can organize community health promotion activities, such as workshops, health fairs, and information sessions, to continually reinforce the importance of measles

prevention. Provide training and capacity-building opportunities for Orang Asli individuals interested in healthcare and community health advocacy. This can empower them to take on leadership roles in health-related initiatives.

Interviews with participants aged 50, villagers passively participate in village development. Most roads and water wells are constructed with substantial financial and logistic support and management from the government and national NGOs. This partly reflects changes in ideas of the role of government, and in some cases, the implementation style of development agencies and NGOs. Villagers have contributed some labour, such as digging water drains along the road in front of their own houses. While this involvement is sometimes relatively spontaneous, it often follows the explicit requests of outside organizations, which undertake development activities on the provision that householders contribute in cash or kind. The rationale is that by contributing, people will have greater ownership of the projects, and so will participate in their maintenance. But various factors discourage community engagement and involvement. Villagers believe that the level of trust among them decreased significantly towards non-indigenous communities they feel inferior due to lack of education and low socioeconomic status. As one woman explained, “they are more comfortable with the existing way of life and asking the government to pay more attention to them” (In-depth interview, 9).

Physically there are many facilities provided by the government such as multi-purpose halls, house repairs, clean water supply and toilet facilities. Nevertheless, the standard of living of villagers has also declined. Most villagers reported that, over time, they have had poorer jungle product collection as a result of deforestation for agriculture, climate change and floods in dry and rainy seasons. Most villagers generate too little cash for daily expenses and, so spiralling into extreme poverty. Villagers have to meet direct and indirect costs for medical care to treat sick children. Delays occur because of the difficulty in locating resources, and the poorest households at times have no choice but to rely on home care only. Villagers felt that the level of care and support from others, and from social welfare (JAKOA Malaysia) and public health services, is satisfactory but they trust traditional treatment more. An elderly woman claimed that anytime she experienced a medical issue, her family members would visit her at the Gua Musang Hospital. If a patient could not afford the treatment, there was no price. I received therapy in 2017. I was at the hospital for three days, and the care was hygienic. I initially feared that I would be abandoned because I had no family and no means of support. Even though there is no charge for the hospital's services, I am uneasy because I am worried about how the hospital functions (In-depth interview, 6).

### **Competing Interests Among Community And Stakeholders**

Competing interests among stakeholders in community health problems are common and can sometimes complicate the resolution of these issues. Different stakeholders often have diverse perspectives, priorities, and agendas, which may not always align. It is not uncommon for people to have reservations about sharing their health problems or for some individuals and families to prefer traditional treatments, especially in certain cultural contexts.

Political interest in the health needs of the Orang Asli Bateq community, an indigenous group in Malaysia, can vary depending on government policies, public awareness, and specific circumstances. The Malaysian government has had varying levels of interest in addressing the health needs of indigenous communities, including the Orang Asli Bateq. Policies and initiatives have been put in place to improve healthcare access and services for these communities. However, the effectiveness of these policies and the extent of their

implementation can vary. It is important to recognize that the Orang Asli Bateq, like many indigenous communities around the world, have historically faced challenges in accessing adequate healthcare services. The level of political interest can have a direct impact on the quality of healthcare services, infrastructure development, and overall well-being of these communities. Advocacy, awareness-raising, and engagement with political leaders continue to be important strategies for addressing the health needs of the Orang Asli Bateq and other indigenous groups.

### **Use of Modern Vs Traditional Treatment Among Community Members**

The study show, there are several reasons why people may be hesitant to openly discuss health issues and choose traditional treatments: **Cultural Beliefs:** Cultural beliefs and traditions often play a significant role in healthcare decisions. Some cultures have deep-rooted beliefs in traditional healing practices and may view them as more aligned with their cultural and spiritual values. **Stigma and Shame:** Health conditions, especially certain illnesses, or mental health issues, can carry stigmatization and shame in some societies. Individuals or families may fear discrimination or judgment if they disclose their health problems openly. **Privacy Concerns:** Some individuals value their privacy and may not feel comfortable discussing personal health matters, even within their own family. They may see health issues as a private matter. **Lack of Trust:** Trust in modern healthcare systems can vary. Some people may have had negative experiences with healthcare providers, leading to a lack of trust in medical institutions. **Limited Access to Healthcare:** In some areas, access to modern healthcare services may be limited or expensive. Traditional treatments may be more accessible and affordable. **Cultural Competence:** Healthcare providers who are not culturally sensitive or do not understand the cultural context of patients may not effectively communicate with or address the concerns of individuals from diverse backgrounds. **Holistic Health Beliefs:** Traditional healing practices often take a holistic approach to health, addressing not only physical symptoms but also spiritual, emotional, and social aspects. Some individuals prefer this holistic approach over the more clinical approach of modern medicine. **Generational Influence:** Family and community traditions are often passed down through generations. If previous generations have relied on traditional healing methods, it can influence the healthcare choices of younger generations. **Fear of Diagnosis:** Some individuals may fear receiving a formal medical diagnosis, as it could confirm a serious health issue. Denial or avoidance of healthcare may be a coping mechanism.

### **Community Decision Making And Participation**

Cooperation and participation of the Orang Asli Bateq community in village life and development are essential for their well-being and the overall progress of their communities. Cooperation and participation within the Orang Asli Bateq community are driven by their cultural values, traditional practices, and a shared sense of identity. External support from organizations, government agencies, and civil society can play a crucial role in enhancing their capacity for community development and self-determination while respecting their cultural autonomy.

The concept of "tolong-menolong" described in the context of Orang Asli suku Bateq is a form of reciprocal cooperation and mutual assistance that plays a crucial role in community life and development. It involves villagers working together and sharing outcomes to support each other. Study finding show some key points to highlight about "tolong-menolong" in this context: **Shared Hunting Animal:** One dominant form of "tolong-menolong" in these villages

involves shared hunting animal. Villagers also raise fruits that belong to another household. This practice helps spread the benefits of hunting animal while reducing individual households' risks and resources. **Mutual Benefits:** "Tolong-menolong" is characterized by its mutual benefits. It fosters a sense of interdependence and cooperation among villagers, enabling them to achieve common goals and share in the outcomes of their collective efforts. **Socioeconomic Status:** "Tolong-menolong" typically occurs between villagers of relatively equal socioeconomic status. This means that those who are economically disadvantaged may be included from certain forms of "tolong-menolong" due to their inability to reciprocate in kind or cash. The transition to a cash-based economy has had an impact on traditional forms of "tolong-menolong." As families increasingly lack the means to reimburse in cash or kind, traditional reciprocal assistance has become less common. The shift to a cash economy can disproportionately affect economically disadvantaged villagers, as they may struggle to participate in "tolong-menolong" due to financial constraints. This can result in a loss of the traditional social safety net for these individuals and households. In summary, "tolong-menolong" is a form of reciprocal cooperation and assistance that has historically played a vital role in the social and economic life of Orang Asli suku Bateq. While it has evolved and faced challenges with the transition to a cash-based economy, its significance in building and maintaining community relationships remains an important aspect of village life.

### **Participation In Prevention And Control Of Disease**

The level of participation in the prevention and control of infectious diseases among the Suku Bateq, can vary depending on several factors, including access to healthcare, awareness, education, cultural beliefs, and government initiatives. Study findings show that some key points to consider: **Access to Healthcare Services:** The level of participation in disease prevention and control can be influenced by the accessibility of healthcare services to the Suku Bateq. If healthcare facilities are readily available and accessible, community members are more likely to seek medical attention when needed. **Awareness and Education:** Awareness campaigns and education programs on infectious disease prevention and control can significantly impact participation. If the community is well-informed about the importance of practices like vaccination, hand hygiene, and safe food handling, they are more likely to actively engage in disease prevention efforts. **Cultural Beliefs and Practices:** Cultural beliefs and practices within the Suku Bateq community may influence their approach to healthcare and disease prevention. It is essential to work within the framework of these beliefs to ensure culturally sensitive interventions. **Community Engagement:** In some cases, community leaders and traditional healers may play a significant role in promoting health practices and disease prevention. **Government Initiatives:** Government healthcare programs and initiatives aimed at indigenous populations can have a substantial impact on disease prevention. These programs may include vaccination campaigns, health screenings, and access to clean water and sanitation facilities. **Trust in Healthcare Providers:** Trust in healthcare providers is essential for active participation in disease prevention. Building trust between the Suku Bateq community and healthcare professionals can encourage community members to seek medical advice and follow recommended preventive measures. **Social and Economic Factors:** Socioeconomic factors, such as poverty and living conditions, can influence the ability of the Suku Bateq community to adopt preventive measures. Adequate access to clean water, sanitation, and nutritious food can significantly impact disease prevention efforts. **Outbreaks and Emergencies:** In the event of disease outbreaks or emergencies, the level of community participation in prevention and control efforts may increase due to

heightened awareness and immediate health risks. **Collaboration with NGOs:** Non-governmental organizations (NGOs) and indigenous rights groups may work with the Suku Bateq community to promote health and disease prevention. Collaborative efforts can enhance participation in preventive measures. **Long-Term Sustainability:** Ensuring the sustainability of disease prevention efforts is crucial. Long-term engagement, community involvement in decision-making, and capacity-building initiatives can help maintain active participation over time. It is important to recognize that promoting active participation in disease prevention and control within indigenous communities often requires culturally sensitive and community-based approaches. Engaging with community leaders, traditional healers, and local stakeholders is key to developing effective strategies that respect the cultural values and traditions of the Suku Bateq while addressing their healthcare needs. "Residents are busy hunting and gathering forest products. Live with poverty and we can take care of our own health." (Women, FGD, 2).

### **Discussion**

Community involvement in Kuala Koh, Gua Musang, and addressing competing interests among community members and stakeholders in the context of disease prevention and control is crucial for the well-being of the villagers. Kuala Koh is a remote village in Malaysia with a significant indigenous population, and community involvement is essential for addressing various issues, including health concerns. To promote community involvement, several strategies can be implemented especially in education and awareness programs to raise awareness about health issues, including disease prevention and control. Engaging local leaders and health workers to conduct workshops and awareness campaigns is a common and effective strategy for community health promotion and disease prevention. (Agrawal P. et al, 2023, Kengia et al, 2022).

Local leaders and health workers are typically familiar with the cultural norms and values of the community. Knowledge about cultural sensitivity allows them to tailor awareness campaigns and workshops to be culturally sensitive, ensuring that the information provided resonates with the community members (Gradellini C. et al, 2021). Collaboration between local leaders, health workers, and other stakeholders, such as government health agencies and NGOs, can enhance the reach and impact of awareness campaigns. Partnerships can leverage resources and expertise to create comprehensive health promotion programs. Nevertheless, the study shows that the idea of working for the public good is far less familiar. Villagers work individually, including undertaking disease control activities on request, but they are reluctant to encourage each other to do so. Effective cleanliness of home and environment health education is needed to encourage people to undertake such activities on a continuing basis (Tomita A. et al, 2017). There is an urgent need to restore trust, confidence, and cooperation between villagers and in the society. This requires the political commitment of the government (Andrade et al, 2019).

To encourage community involvement in disease prevention, local leader, and health workers must establish feedback mechanisms within the community to collect input and suggestions from residents. This allows for continuous improvement of awareness campaigns and workshops, making them more responsive to community needs (Rifkin S.B. et al, 1996, Haldane V. et al, 2019). Health workers need to build trust and credibility within the community. They are seen as reliable sources of information and can effectively convey health-related messages. Research also has shown that people are more likely to trust and act upon health advice from individuals they know and respect (Birkhäuser J. et al, 2017).

Understanding about cultural sensitivity and familiar with the cultural norms and values of the community allows health workers to tailor awareness campaigns and workshops to be culturally sensitive and ensuring that the information provided resonates with the community members (Kaihlanen A.M. et al, 2019).

Indeed, research has demonstrated that individuals' perceptions of their prospects and well-being can significantly influence their motivation and participation in disease control and prevention efforts. Research has shown hope and motivation, long term health goals, perceive threat, health seeking behaviour and social and economic factors are determined of outlook in healthcare behaviour among community. Having a positive vision of the future filled with good health and well-being can motivate individuals to engage in preventive measures and control strategies and this positive outlook can serve as a powerful driver for adopting healthy behaviors (Duncan A.R. et al. 2021).

People who perceive a healthy future are more likely to invest in their long-term health. They are willing to make lifestyle changes, such as adopting a healthier diet, exercising regularly, and avoiding risk factors, to ensure a healthier future. Conversely, individuals who have a pessimistic view of their future health may perceive a higher threat from diseases. This perceived threat can motivate them to take proactive steps to prevent illness or control existing health conditions and consequently, people show interest in community participation. (Jones C.L. et al. 2015).

The situation in Kuala Koh villages echoes that suspicion, distrust, increasing poverty, food insecurity, unemployment, landlessness, and indebtedness, against the backdrop of natural disaster, contribute to a lack of confidence in government capacity. Its long-term commitment to village development or to improved health, and consequently, people show little interest in community participation to prevent and control the disease. To address these challenges and promote community participation in disease prevention and control, it is crucial to take a comprehensive approach that not only focuses on health but also addresses the underlying social, economic, and political factors contributing to the community's vulnerability. Building trust, addressing poverty and food security, creating employment opportunities, and strengthening local resilience in the face of natural disasters are all essential components of a holistic strategy to improve community health outcomes in contexts like Kuala Koh villages. Moreover, actively involving community members in decision-making processes and tailoring health interventions to their specific needs and concerns can help rebuild trust and stimulate interest in participation (Atkinson et al, 2011, Questa K. et al, 2020).

Studies show that top-down disease prevention and control activities have a temporary effect but do not lead to the behavioural changes and needed to promote sustainable disease prevention and control efforts. By recognizing the importance of community ownership and tailoring interventions to local contexts, it is more likely that behavioural changes and the creation of a clean and safe environment can be achieved to ensure the long-term control and prevention of diseases. The study recommended intersectoral cooperation and stressed the importance of involving local health services, civil authorities, and key community members to encourage individuals to take part in and sustain disease prevention and control strategies (Questa K. et al, 2020, Iqbal F. 2021).

## **Conclusions**

Community participation among Orang Asli populations facing several challenges that may hinder its success. These challenges are often unique to their way of life, cultural practices,

and socio-economic circumstances. Community participation as an approach seems to have been most successful in countries with strong political authority. In contrast, in fragmented societies where community members have different interests and problems, and lack of trust and confidence in political leadership, community participation has faced a significant challenge. Local social, political, and economic factors and associated structural barriers and inequalities compound to affect the ability of members of communities to sustain the activities required of them for disease control. These various factors have influenced the introduction and sustainability of community participation in the country. Community-based programmes involving local responsibility are the only cost-effective and sustainable ways to ensure the elimination of infectious disease affected this poor community. However, in Kuala Koh, community participation has been implemented primarily by international organizations, NGOs, government departments and vertical disease control programmes. Local knowledge and local institutions, including those that would serve to achieve the same goals, have largely been overlooked. In this study, community members claimed that community-based disease control occurred, but, in practice, people had limited opportunity to participate in planning and managing dengue prevention and control in their own villages, and so had little interest in or awareness of the need to ensure that basic control activities were sustained.

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