

# Part 1: Social Determinants Influencing Access to Malaria Services

A Formative Study in NTT, Papua and West Papua

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### **Contents**

Acronyms and glossary ■ iv

SUMMARY ■ v
INTRODUCTION ■ 1
STUDY METHODOLOGY ■ 4
CONTEXT ■ 5

#### **FINDINGS**

- 1. PEOPLE'S BEHAVIOUR IN RELATIONTO MALARIA 8
- 2. PEOPLE'S RESPONSESTO MALARIA 18
- 3. EXPERIENCES OF MALARIATREATMENT 23
- 4. BEDNETS: USAGE AND PREFERENCE **3**3
- 5. PREVENTION PRACTICES 38

STUDY IMPLICATIONS ■ 41

Annexes ■ xi



# **Acronyms and glossary**

ACT Artemisinin-based Combination Therapy

ANC Antenatal Care

API Annual Parasite Incidence is the number of confirmed new cases from

malaria per a thousand population per year

BPJS Badan Penyelenggara Jaminan Sosial (Indonesian national health insurance)

Cadre Kader (community health worker)

COM-B Capability, opportunity, motivation for behaviour change

DHP Dihydroartemisinin-Piperaquine, also commonly referred to as 'the blue pills'

Dinas Kesehatan Government health office at the provincial or district level

Gol The Government of Indonesia
HCD Human Centred Design

HIV/AIDS Human immunodeficiency virus/Acquired immunodeficiency syndrome

IDR Indonesian Rupiah (Indonesian currency)

IRS Indoor Residual Spraying

Kampung Village

LLIN Long-lasting Insecticidal Nets

Malaria tertiana Malaria caused by Plasmodium vivax or Plasmodium ovale

Malaria tropica Malaria caused by *Plasmodium falciparum* 

MalCon Malaria Control, a corporate social responsibility programme on malaria by

Freeport Indonesia

Mantri Male nurse

NMCP National Malaria Control Programme

NTT Nusa Tenggara Timur (East Nusa Tenggara)

Ojek Motorbike Taxi

PDD People-Driven Design

Posyandu Pos Pelayanan Terpadu - community-based integrated health services aiming

to provide basic health services to members of the community e.g. clinic sessions for mothers and young children and the elderly, family planning,

nutrition, immunization and disease control

Primaquine Antimalarial drug that prevent relapse in vivax and ovale malaria, also

commonly referred to as 'the yellow/brown pills'

Puskesmas Pusat Kesehatan Masyarakat (community health centre)

Pustu Puskesmas Pembantu (local health centre, supporting the puskesmas

RDT Rapid Diagnostic Test

RT Rukun Tetangga/neighbourhood administrative unit

RW Rukun Warga/community unit
SBC Social Behaviour Change

SBCC Social and Behaviour Change Communications

TB Tuberculosis

Transmigrant People who move to other province as part of government migration programme

UNICEF United Nations Children's Fund WHO World Health Organization

Exchange Rate (March, 2021)

1 USD = 14,356 IDR 0.70 USD = 10,000 IDR

### **SUMMARY**

#### Background, methodology, study locations and participants

This report is Part 1 of two parts and presents the main findings of formative research undertaken between January -March 2021. Empatika was commissioned by UNICEF to undertake formative research to understand the factors affecting access to malaria services in high endemic settings and support the search for local solutions to intransigent behaviour change challenges which risk attainment of the Government of Indonesia goal of malaria elimination. The findings are expected to feed into the design of the National Malaria Control Programme's communication strategy. The research was implemented through adapted immersion and people driven design (PDD) (which is based on Human Centred Design (HCD)). Both approaches are strongly participatory and put study participants at the centre of identifying barriers, the need for change and co-designing the means for change. This report presents the insights from the adapted immersion phase of the research.

For the adapted immersion, Empatika research team spent extended times with families over several days and early evenings rather than the usual practice with full immersion of living with families overnight. This was to mitigate the infection risk posed by COVID-19 to both researchers and participants. The five days immersion aimed to understand the local context for malaria service access and people's behaviours in relation to malaria prevention and treatment. Participatory barrier analysis was specifically used to identify enablers and barriers to adopting positive behaviour. The subsequent PDD process built on the

insights collected through the adapted immersion by facilitating the generation and testing of local means to promote positive behaviour change. The research covered eight locations across four districts: South West Sumba, NTT; Manokwari, West Papua; and Mimika and Jayapura, Papua. In each district, there were two sites selected which made a total of 8 study locations. These were selected in consultation with UNICEF and local government partners. The criteria used in selection of locations included malaria prevalence, geography, relative accessibility to health services, and demographic characteristics (livelihoods, ethnicity, socioeconomics). Overall, Empatika researchers interacted with approximately 877 people over the course of the research. These include focal families and their neighbours, health service providers, other service providers (e.g., village officials, faith leaders, kiosk owners) and other community members, and specifically including youth. The findings are presented as far as possible as the views of the people we met and talked with. Researchers' observation and direct experience were also included to provide context and triangulation.

The findings of this study are presented in five main sections. The first section on people's behaviour in relation to malaria covers how people understand and view malaria. This serves as a key starting point for understanding other findings. We have adopted the framework used by the Government of Indonesia in its malaria intervention policy to structure the findings: detecting malaria, malaria treatment, bednets usage and preference, and prevention practices.

# 1. People's behaviour in relation to malaria

Across all study locations people shared how their perception and attitudes of malaria has changed over time. They recalled the time before the 1980s when malaria was rampant, resulting in deaths. They noted malaria services' roll out intensified in the 1990s. Quinine pills became widely available and puskesmas construction accelerated giving people local access to services. Some people were tested for malaria for the first time. By the 2000s, there were less malaria deaths and less reported malaria infections, both among the local populations and the transmigrant communities. In 2007-2008, Dihydroartemisinin-Piperaquine (DHP) pills were introduced to the area along with primaquine. The medicines effectively reduced malaria symptoms, making malaria no longer seen as a life threatening disease by people in the area. By the mid 2010s, a range of malaria programmes were implemented across the study locations by the government, NGO and private foundations.

Almost everyone we talked with has contracted malaria at least once. Children and teenagers expect to get malaria every year. Adults rarely experienced malaria recently, even though they had contracted malaria before, usually when they were younger. People found it difficult to recall any last known death due to malaria in the past 5-10 years.

Because malaria is nowadays perceived to be infrequent among adults and death almost never happened due to highly effective medications being available, people across study areas were not highly concerned about contracting malaria. People often said that malaria was an inseparable part of their lives. Some even used malaria as a yardstick to being acclimatized to the place, particularly migrants and incomers. Most people did not think malaria could be eliminated from their area.

Compared with malaria, there are other diseases that people in all study locations are more concerned about. Those that have more severe consequences, including death, need surgery and are expensive to treat, are seen as more concerning. Diseases that affect daily lives and are transmittable (such as HIV/AIDS or TB) are also a source of worry for people we talked with.

People consider themselves quite knowledgeable about malaria. Because most people had had malaria at least once, they could distinguish different malaria types and their symptoms. Local Papuans shared that they feel they cope with malaria better than migrants as they continue to work while migrants need to rest.

People describe a range of causes of malaria with mosquito transmission rarely the first explanation. The most commonly mentioned cause is a weak or low immune system due to being tired or stressed out, lacking sleep or rest and not eating well. Conversely, people believed that a strong body could prevent malaria.

People also blame the weather as the cause of malaria; cold or rainy weather and rapid changes in temperature. Living in certain geographical situations such as mountains, coast, or areas with plenty of trees and bushes, are also noted as causes of malaria. Most health providers did refer to mosquitoes as the main cause of malaria although some mentioned other causes with weak immune system the most often mentioned.

People across the study locations have little knowledge about malaria transmission. Very small numbers of people specifically mention malaria as being transmitted through mosquito bite from a sick person to another.

Despite not immediately linking mosquitoes to malaria, people are very aware of the presence and prevalence of mosquitoes. They notice when mosquitoes tend to be more active such as in the evening, during rain and fruit season. People are also very familiar with where mosquitoes

were more prevalent in their areas. They mention outdoor areas (puddles, fields, garden, forest), dirty places where there is a lot of trash (clogged sewers, toilet areas), animal pens, and flooded areas (under the house, under wooden walkways).

People tend to use the phrase 'no mosquitoes' to mean that there were not as many mosquitoes in that place compared to other places and NOT that there were no mosquitoes present. They often mention there was no mosquito inside the house in general compared to being outside.

People said that they find mosquitoes a nuisance but they put up with them, especially when they were working, as they focused more on the activities to be done and their livelihood needs. People are particularly annoyed when mosquitoes disturb their sleep but they do not really talk about being unhappy with mosquitoes because they were linked to malaria.

#### 2. Detecting malaria

Across all study locations, people either self-diagnose or wait and observe their fever for a few days before deciding to visit health providers. Those who self-diagnose assume having a persistent fever indicates malaria, based on previous experience and purchase over the counter non-prescription malaria drugs from local pharmacies and kiosks without testing for malaria. People who prefer to wait and see usually wait for two to three days, some up to one week, before seeking medical care. In the meantime, they take paracetamol and/or use local remedies to treat their fever and headache. If the fever remains or worsens and they experience other symptoms such as shivering or severe headache, they visit health providers to test for malaria. Men (and older teen boys) were significantly less likely to seek tests than other members of the family.

Parents delay reacting to their children's fever because of a widely held perception that as part of growing up children develop fevers often. People also wait because they are advised to do so by health providers because fever may be caused by a virus which may take several days to detect. The only exception was in Sumba Remote. There, people immediately visited the private foundation clinic on the first day of getting a fever and were tested for malaria.

When people do decide to test for malaria, they prefer trusted providers such as malaria cadres or a favorite doctor. People also preferred to go to a provider that was nearby or places where treatment did not incur cost. They likewise preferred places with short queues and a quick process. Where there was choice, people often preferred private health services as they were regarded as more efficient and convenient despite cost.

People sometimes receive unexpected malaria test results; they are tested negative for malaria but continue to have the symptoms resulting in distrust of the test and re-testing where possible in a different facility. Puskesmas testing laboratories were often the least trusted. People are aware that the rapid diagnostic test (RDT) does not always provide accurate malaria assessment compared to a microscopic test.

Yet, for some people, such as those in remote locations, only RDTs are available due to distance to or limited resources at microscope testing laboratories. When given a negative test people sometimes suggest that taking medication, usually paracetamol, before the test had interfered with the test result.

#### 3. Malaria treatment

In all locations, where formal health services are sought, malaria is mostly treated with oral medicines which typically include DHP and primaquine. People are usually given three tablets of DHP per day for three days and one primaquine tablet per day for one day to treat malaria tropica or for 14 days to treat malaria tertiana. The dosage was adjusted to their age and weight.

Other than DHP and primaquine, other malaria medicines such as suldox, quinine and chloroquine are also available in some study locations. These pills are easily accessible at clinics, pharmacies or kiosks and they can be bought without prescription.

Most people taking malaria pills said they would only take them until they feel better, assuming their malaria was gone. This could be as early as one day or just one round of medication. People also stopped taking malaria pills due to side effects. As people start to feel better, they notice side effects (buzzing ears, loss of hearing, nausea, headache) more and decide to discontinue the treatment. Some others said they stopped the medicine because they continued to have symptoms and therefore thought it did not work.

Generally, men tend not to finish medicines compared with women. Some children and teenagers do finish their medications especially if their mothers monitor them. Some people said that they do not receive specific instruction to complete the medicines while some others said they did receive advice to finish the medicines from the health providers. Health providers sometimes ask people to come back to retest for malaria after completing the medication, but they could not follow this up.

# In a household, mothers usually take family health decisions and they are particularly concerned about their young children's health.

Mothers across all study locations monitored children's symptoms, gave children paracetamol if deemed necessary and tried home remedies. Only if the children did not get better, mothers took them to clinics, puskesmas or to a cadre to be tested for malaria.

Teenagers usually tell their mothers when feeling unwell and follow what they are told to do although teenage boys often only share this when they find pain and other symptoms 'unbearable'. They depend on their mothers to take care of them including taking them to health

providers. Sometimes, fathers also accompany them, especially when travelling is required.

Adult men tend to delay treatment and ask their spouses to get medicines for them. Men treat themselves with herbs or kiosk medicines or leftover malaria medicines if they have any without getting tested. Men usually only go to health providers when they feel really sick.

# For most people, puskesmas is their first point of contact when seeking malaria test and

**care.** People in most study locations could access the puskesmas in their village or ones located nearby. The exceptions were those who lived in Jayapura Lake, Sumba Remote and Sumba Peri Urban where the puskesmas were located some distance away from their village and people had to pay transportation costs to go there.

Some puskesmas do not have staff able to conduct microscopic tests. Those who can often indicate that they dislike the work which strains their eyes. In one puskesmas, reagents needed for the testing were diluted in the effort to produce quicker test results but which led to inaccurate tests.

Puskesmas struggle to manage stocks of malaria testing and treatment supplies. In some locations, puskesmas staff had to limit the number of malaria tests so they would not run out of supply before restocking, a problem exacerbated during 'malaria season'.

One puskesmas washed slides already used in malaria tests with negative results and reused them. People are often dissatisfied with puskesmas' service, noting it is slow and there are often long queues. In some locations, people mentioned that puskesmas' staff were unfriendly. Limited operating hours in all puskesmas (especially for diagnostic test services) sometimes result in delayed testing and treatment particularly when patients have to travel far to the puskesmas. Despite dissatisfactions, puskesmas services are used because they are completely free and often more affordable than private services. This is especially

relevant in some locations in Papua where private health services are commonly available. **Across all locations, most people prefer private clinics or private hospitals.** They consider the service in private clinics and hospitals to be good, specifically appreciating the absence of long queues.

Specially designated malaria cadres were only found in three of the eight study locations and only in Papua. People generally trust and feel able to communicate well with these local cadres.

Malaria cadres are usually equipped with RDT kits as well as complete malaria pills

including DHP, primaquine and paracetamol which they restock from the puskesmas. All cadres try to make sure that people take their malaria pills as prescribed. Some make home visits to check whether people use bed nets and take photographs of nets in use. Physical access to health services is mostly good with puskesmas located in the village and in some places, pharmacies, clinics and hospitals were also nearby. However in some locations the nearest health services are far and/or accessed via poor roads with limited transportation options. Some puskesmas or villages arrange transportation but this was not always available and reserved for emergencies.

# 4. Bednets: usage and preferences

Across all study locations all families have bednets and use on a daily basis. However, bed nets are used most consistently when mosquitoes are prevalent.

Women, children, and toddlers use bed nets more often and consistently while teenagers (especially boys) and men tend to use less or not at all. Teenagers often sleep without bed nets because they frequently fall asleep before having had the time to set up the bed nets. Men tend to not use bed nets as they like sleeping where there is breeze which, in turn, they claim

keeps mosquitoes away. Although rarely using bed nets at home, men do use bed nets when overnighting in the forest when harvesting sago, collecting forest products and hunting.

People's primary reason for using bed nets is relief from bothersome mosquitoes and not concern about malaria. Those who do not use bed nets note that bed nets are too hot or feel restricted or uncomfortable, especially when the bed net is too small or the house is too small for a bed net.

People usually receive their bed nets from puskesmas and they have been receiving bed nets every year since the mid-2010s. It is common for people to have surplus bed nets, so people store them, give them away to relatives or repurpose them.

The new green bed net distributed by the Government in October 2020 is widely

disliked. People describe the bed net as rough and stiff, smells strongly, irritates the skin, and also has bigger holes than previous nets distributed. The old bed nets (referred to as 'the white ones') were generally preferred. People told us that the white bed nets were softer, more comfortable, and smelled better.

### **5. Prevention practices**

malaria.

People in the study locations do not often use any particular prevention against mosquitoes even though mosquitoes frequently bite and irritate. People only took precautions when mosquitoes were prevalent because, like the use of bednets, of annoyance rather than to prevent

At home, often the only preventative measure practiced is using bed nets while only a few use fans to blow away mosquitoes or use mosquito spray in the house. Other measures were only adopted when working in the forest or the farm where mosquito numbers were high. In these circumstances, people may use

topical repellants, wear long sleeves or make smoke to keep mosquitoes away. Across study locations, there has been no recent indoor residual spraying (IRS) programmes where they have had previously. The two Timika locations benefitted from an annual programme of IRS organized by the Malaria Center supported by the Malaria Control (MalCon) team, a Corporate Social Responsibility programme by Freeport, but the extent of this has also recently been reduced. Four of the study sites had never received IRS.

### People's driven solutions for malaria elimination: transitioning findings into action.

The immersion research has revealed insights into context and behaviours which inhibit the potential to attain the Government of Indonesia's intention to eliminate malaria by 2030. Spending considerable time immersed in villages and communities and experiencing first hand the context and people's day to day realities enabled deep engagement with and understanding of the determinants affecting positive SBC. Following analysis of the findings, some factors emerged as particularly significant and were judged to be amenable to local solution generation. Others which are critical to malaria elimination are systemic, such as provision appropriate and timely malaria prevention, testing and treatment resources and require policy and resource mobilisation to address and are therefore beyond the scope of the design phase of this study.

Those factors which warrant local attention and are judged to be do-able at local level and likely to contribute significantly to improved malaria related outcomes were prioritised for phase 2 of the formative research. These are the need for (i) early testing for malaria, (ii) completion of malaria medication, (iii) highlighting those at particular risk and the risks to others of undetected

asymptomatic/low symptomatic malaria, and (iv) building better relationships between health services and communities and within communities to combat malaria together.

Using the internationally recognised COM-B (Capability, opportunity, motivation for behaviour change) framework to aid SBC intervention design, the immersion research has revealed that motivation to change behaviour is the most challenging aspect. Generally people do have, with some caveats, access to services and the means to change behaviour (opportunity) through local testing and treatment provision, access to bednets and some local mosquito control programmes. They also mostly have the knowledge (capability) about malaria although there is a major gap in understanding transmission. However, since malaria is no longer considered serious or fatal with the introduction of easily obtainable modern medication, the motivation to change behaviour is significantly lacking and people are prepared to endure malaria.

Part 2 of the report (provided as a separate document) presents the people-driven design process facilitated with four of the eight immersion study communities which intended to develop workable solutions to encourage behaviour change. In line with recent evidence across countries and SBC programmes 'providing target populations with specific actionable steps through SBCC was found to be more **successful'** than just 'communicating the risk of malaria and giving access to necessary tools such as ITNs and RDTs ", the PDD therefore focused on specific actionable steps and was led by what people in communities themselves consider relevant, relatable and do-able with the resources they already have.

### INTRODUCTION

The Government of Indonesia (GoI) initiated the National Malaria Control Programme (NMCP) in 1959, which was hampered by the resistance to Dichlorodiphenyltrichloroethane (DDT) indoor spray to control malaria. Then in 2008, the NMCP renewed its commitment to achieve malaria elimination by 2030 to meet the Sustainable Development Goals. The malaria prevalence based on Annual Parasite Incidence (API) decreased from 1.75 (2011) to 0.84 per 1,000 population (2018) (World Health Organization 2017). From 2007 to 2017, confirmed malaria cases were reduced to half and 72% of the population of Indonesia live in more than 260 malaria free districts, largely in Java and Bali.<sup>2,3</sup>

This progress is attributed to various nation-wide supply driven interventions which include prevention through LLINs distribution and IRS, accurate diagnosis and standardised treatment, as well as stronger surveillance system. Long-lasting insecticidal nets (LLINs) have been distributed in high endemic areas every three years, along with campaigns to encourage net usage. LLINs have also been distributed through antenatal care (ANC) services to encourage protection among pregnant women and children. There were 20 million LLINs distributed from 2007 to 2017. Insecticide

treated bed nets have been proven to reduce morbidity rate of children under 5 by about 20%<sup>5</sup> and contribute to vector control by shortening mosquito's lifespan. LLINs maintain effective levels of insecticide for at least 3 years even after repeated washing. For LLINs to work effectively, it requires wide usage in a community—Indonesian government aims for 85% net use when sleeping by 2021 (National Action Plan for Acceleration of Malaria Elimination 2020-2024).

Other preventive measures have also been introduced at household and community levels. For instance, campaigns on environmental control to reduce mosquito breeding sites and campaigns to encourage bed nets usage during sleep. Regular indoor residual spraying (IRS) has been implemented along with the initiation of community-based malaria posts (Posmaldes) to promote malaria control and to report early detection. When doing outdoor activities, people in high endemic areas are encouraged to, for instance, wear clothes with long sleeves and mosquito repellent.

Malaria interventions also include early detection using rapid diagnostic tests (RDTs) and microscopes, and prompt treatment. Early detection is crucial because it can lead to effective treatment by taking medicines in the first 24 hours of having symptoms for three consecutive days (Ipa 2018). Artemisinin-based Combination Therapy (ACT) was introduced in 2004 as first-line treatment because of widespread chloroquine resistance in Indonesia. Laboratory confirmation, including rapid diagnostic tests (RDT) to complement microscopy tests, was mandated shortly thereafter which resulted in improved reporting and surveillance.

Malaria elimination in Indonesia: halfway there. Lancet Global Health. 2018 Jun;6(6):e604-e606. doi: 10.1016/S2214-109X(18)30198-0. Epub 2018 Apr 24. Accessed on 30 sept 2020.

<sup>&</sup>lt;sup>3</sup> This data is challenged as being under-reported and under-estimated since it was collected from district-level hospitals only. No data was gathered from sub-districts Puskesmas or other sources (National Malaria Control Programme Review, 2011).

<sup>&</sup>lt;sup>4</sup> "Kebijakan Malaria, Rencana Aksi Eliminasi Malaria 2020 - 2024" presented by Malaria Sub Division, Ministry of Health, at Pertemuan Monev dan Perencanaan Programme Malaria 2020. Accessed from

https://drive.google.com/drive/u/0/folders/11|2Q-uKuLB47q\_-lsXQBSSwSxGHC\_c3H

<sup>&</sup>lt;sup>5</sup> Based on trials in several African communities https://www.cdc.gov/malaria/malaria\_worldwide/reduction/itn.html

However, despite progress, declines in malaria prevalence are plateauing, and renewed focus is critical, particularly in three eastern provinces: Papua, West Papua, and East Nusa Tenggara (NTT). In 2017, the World Health Organisation (WHO) estimated there were 1.5 million malaria cases and an estimated 2,700 deaths in Indonesia. However, only 261,617 cases and 47 deaths were confirmed and reported by the national malaria information system (World Health Organization 2017).6 In 2019, about 94% of malaria cases in Indonesia were reported from Papua, West Papua and NTT provinces. 7 This was attributed to a number of determinants, including unique bionomics (mosquito habitats and biting behaviour), lack of testing, lower capacities of health services, poor housing and livelihood related factors such as malaria transmission among migrant workers in forestry, mining and plantations. Shortages of malaria drugs and RDTs in these provinces are also common and 30-40% of Puskesmas staff in these areas were noted to have had no malaria training at all.8

Empatika's desk review (submitted to UNICEF on 30th December 2020) proposed an examination of social determinants which are crucial in shaping malaria interventions and its effectiveness. The Government of Indonesia has delivered malaria programmes, across malaria endemic areas, in the form of prevention through bed nets distribution and IRS, detection and treatment,

and surveillance, yet malaria prevalence remains a challenge in high endemic areas. For instance, many communities had low bed nets usage and implemented minimum prevention practices. Many living in high endemic areas also tended to self medicate and did not receive the recommended treatment (ACT).

Current literature has identified many social factors related to malaria interventions such as education level, income, occupation, knowledge about malaria and transmission, belief in traditional/modern medicines, and preventive actions. However, most analyses have yet to explain how these determinants affect people's access and behaviour towards malaria services.

The document also reviewed Social and Behaviour Change Communication (SBCC) and Human Centered Design (HCD) approaches in malaria and health programmes. Both show that understanding people's perspective and experience can feed into contextual programmes for behavioural change. The table below shows the findings from the desk review about social determinants that affect access to malaria services and behaviour (Also see Empatika's Desk Review Report for full details).

Empatika was commissioned by UNICEF to conduct a formative research to understand the changing dynamics of malaria services in Papua, West Papua and NTT. Empatika's approach utilizes participatory methods to put people at the centre of the process to identify behaviours and to define a more relevant, appropriate and effective communication strategy to achieve malaria-free Indonesia. This report presents the findings from this study through the implementation of adapted immersion for community assessment and barrier analysis. Part 2 of the report describes the subsequent people-driven design phase of the study which led to the trialing of community-led communication approaches.

<sup>&</sup>lt;sup>6</sup> This confirmed data was collected from district-level hospitals only. No data was gathered from sub-districts Puskesmas or other sources (National Malaria Control Programme Review).

<sup>&</sup>lt;sup>7</sup> https://www.kompas.com/sains/ read/2020/08/15/100000723/tren-kasus-malariadi-papua-meningkat-apa-penyebabnya-?page=all. Accessed on 30 Sept 2020

<sup>&</sup>lt;sup>8</sup> Gani, A & Budiharsana, MP 2019, The Consolidated Report on Indonesia Health Sector Review 2018 -National Health System Strengthening, accessed December 29, 2020, from <a href="https://www.unicef.org/">https://www.unicef.org/</a> indonesia/reports/consolidated-report-indonesia-health-sector-review-2018>

<sup>&</sup>lt;sup>9</sup> Empatika 2020, Desk Review Report: Formative Research to Describe the Social Determinants Which Affect Access to Malaria Services and to Advise the Implementation of Communication for Behaviour Change Towards Effective Malaria Control in HIgh Endemic Provinces of Papua, West Papua and NTT.

Behaviour

Communities in high endemic areas have access to malaria services (bed nets, healthcare facilities, mass campaigns). However, there are **challenges in accessing** these services such as low use of bed nets during sleep, distance and transportation cost to reach health facilities, low awareness of nearby healthcare services, and clarity of message about bed nets. Studies have associated these challenges with social factors, but yet to explain why people choose certain actions or how those factors affect their decision in accessing malaria services.

People's preferences in seeking treatment are self-medication through buying medicines from local kiosks. In some areas, people prefer private rather than public health providers although public facilities provide free treatment.

Malaria treatment delivery in high endemic areas face some challenges. More than 65% of people who sought treatment in high endemic areas did not receive ACT as the recommended treatment, which meant treatment may not be as effective. Single screening and treatment for pregnant women was inconsistent due to lack of testing tools and lack of health providers' capacity.

Knowledge. People were aware of malaria disease and symptoms. Knowledge about malaria is associated with socio-economic factors such as education level, occupation, and poverty. However, there is a gap in understanding malaria transmission. Also, there seems to be little understanding of asymptomatic malaria which, when undetected, can maintain transmission among humans.

Attitude. Attitude towards malaria and therefore people's responses to the disease may be shaped by local context. Communities rely on local wisdom to treat malaria such as using local herbs or not eating certain foods. People in some high endemic areas perceive malaria as an ordinary part of their lives over which they have little influence. There are differences too among locals and non-locals towards malaria with the latter group showing higher awareness of malaria prevention than the locals.

**Practice.** Despite bed nets' effectiveness in preventing malaria, low usage is evident across high endemic provinces. Studies have explained this due to inconvenience, affordability, not fitting with the house and prioritising bed nets for some members of the family. Another commonly found practice is delay in treatment seeking. Studies found that many perceived fevers are a result of change of season rather than malaria symptoms. Statistical analysis has associated this delay with economic background, origin whether someone is local or a migrant and treatment preference, but yet to explain why people delay to treat their illness

# STUDY METHODOLOGY

The formative study followed participatory methods to put people at the center of the process. The research focused on deep situational assessment in particular to understand the barriers and enablers of target groups to access malaria services, and factors affecting this in order to find the best ways of reaching the target groups and motivating behaviour change. A detailed description of the study methodology is available in Annex 1.

The study started with a **desk review** to review social determinants, enablers and barriers affecting access to malaria services and positive behaviour. Gaps of knowledge that were identified in the desk review then informed the study design. The second stage was data collection through adapted immersion in which we focused on (i) participatory community assessment and (ii) participatory barrier analysis. Both were done throughout five days of the adapted immersion in which researchers visited the communities during the day and early evenings. In the participatory community assessment, we looked into understanding the community context particularly related to access to malaria services and community members' behaviours towards malaria intervention. In the participatory barrier analysis, we identified enablers and barriers to adopting a particular behaviour.

Analysis of these findings then fed into the People Driven Design **process facilitated at community level.** Researchers returned to one of the locations in each district, facilitated workshops with the communities and the service providers to develop potential solutions. These recommendations were consolidated and added to the research findings from the earlier phases, to produce this report.

The overall adapted immersion had researchers interacted with an estimated total of approximately 889 people.

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Table 2 below presents an overview of the study participants across all locations.

 Table 2: Study Participants for Adapted Immersion

Categories	SW. Sumba		Manokwari		Timika		Jayapura	
	М	F	М	F	М	F	М	F
Infants and children under 5 year old	5	7	5	9	4	3	5	5
Children	11	6	5	4	40	8	18	20
Adolescents	25	25	10	22	17	13	18	23
Adults	38	37	20	49	28	38	19	25
Elderly	4	9	19	18	13	11	15	17
Pregnant women or recently pregnant women	-	5	-	6	-	6	-	2
Health providers e.g. traditional healer, doctor, midwives, nurse, mantri and health cadre	11	1	6	9	6	22	0	6
Service providers in the village e.g. teachers, NGO, village official, faith leaders, kiosk owners, medicine sellers	7	11	27	20	29	19	12	16

Total

Male = 417; Female = 472

# CONTEXT

Locations for this study were initially recommended and discussed with UNICEF and the reference group. All districts have high endemic malaria. In each district, the research team visited two locations which were then selected in consideration of variation e.g., population characteristics (Papuan, migrant), access to health services, urban/peri urban/rural, and geographical landscape (forest, coastal).

### **JAYAPURA FOREST**



Geographical setting	Rural, valleys, plains, open lands and forest			
Type of housing	Majority (80%) are brick houses and some are wooden houses on stilts. Wooden houses have gaps in the walls.			
Religion	Kampung 1: Moslem Kampung 2: Christian			
Population, ethnicities	Kampung 1: ~2,000 people covering 4-5 RWs. Mostly migrants	Kampung 2: ~1,000 people covering 4-5 RWs. Mostly Papuans		
Main livelihoods	Kampung 1: farming and raising livestock, trading, waged labor (teacher, nurse, store assistant), construction workers	Kampung 2: farming and raising livestock, trading, sawmill		
Access to health services	Puskesmas in Kampung 1; health clinics run by retired or current health providers and a local pharmacy are available in kampung. There are currently 3 active malaria cadres. Hospital in the city (1.5 hours)			

### **JAYAPURA LAKE**

Geographical setting	A kampung just by the Sentani lake. This is the most distant kampung from Puskesmas in Sentani city. 30-45 minutes from district capital with very limited (no) public transportation
Type of housing	Wooden houses on stilts and brick houses (part of government assistance)
Religion	Christian
Population, ethnicities	Around 170 households spread around the Sentani Lake side. Mostly Papuans.
Main livelihoods	Fishing for income earning and subsistence farming (corn, cassava, sweet potatoes, beans, vegetables, papaya, pumpkin)
Access to health services	Pustu in the kampung but there have been no staff since 3 years ago. Nearest formal health providers are District Puskesmas (45 minutes by car or ojek) or Puskesmas in the city.
	Have 3 malaria cadres since 2016.



### **MANOKWARI URBAN**



Geographical setting	Urban area, city centre with government offices, main market, shops and banks
Type of housing	Mostly brick houses, use zinc roofs
Religion	Papuans are mostly Christian, migrants are Moslems
Population, ethnicity	~6,000 people in the village covering 10 RWs.  Papuans and migrants (Sulawesi, East Java)
Main livelihoods	Trader at market, kiosk owner, ojek driver, food vendor, fishermen/women, civil servant, teacher, health provider
Access to health services	Local pharmacies, private clinics, Puskesmas, hospital

### **MANOKWARI RURAL**



Geographical setting	Rural area along a coastline and forest/small hills
Type of housing	Mostly brick houses of which many are part of government assistance programme. Use zinc roofs.
Religion	Christian
Population, ethnicities	±300 households/±1,000 people spread covering 3 kampung  Mostly Papuans, few migrants from Sulawesi.
Main livelihoods	Farmer, fishermen/women, construction worker, teacher, kiosk owner, seasonal driver
Access to health services	Puskesmas located in the village; hospital and private clinics in the city

### **TIMIKA CITY**



Geographical setting	Urban, lowland
Type of housing	Mostly brick houses, few stilted wooden houses among Papuans
Religion	Christian and Moslem
Population, ethnicities	~5,000 people (2015 data) across 22 RT, excluding unrecorded seasonal migrants.  Papuan and migrants
Main livelihoods	Ojek drivers, formal and informal/illegal miners, petty sellers, kiosk owners, house maid, construction labour, government official, teachers, landlord ( <i>kontrakan</i> ), factory workers in Kuala Kencana
Access to health services	Private hospital by Freeport (15 minutes motorbike ride)

Geographical setting	Rural, swampy lowland surrounded by forest, mangrove, rivers. Access is >3 hours boat from the city's port to the district.
Type of housing	Mostly wooden houses on stilts with iron roofs. Cement houses are for service providers.
Religion	Majority Catholic, others are Christian and Moslem
Population, ethnicities	~2,000 people/600 households. Few migrant families (around 20 families).
	Majority are Papuans and some migrants from other Papua provinces, Sulawesi and East Nusa Tenggara.
Main livelihoods	Subsistence farmers and fisherman. Some others are government officials, teachers and health workers
Access to health services	Puskesmas is in the furthest village. No laboratory technician since August 2020, only RDT test available conducted by 2 nurses. Hospitals are in the city.

### **TIMIKA ISLAND**



#### Rocky coastline, people mostly live inland. Geographical Many unused land areas with bushes. People setting live close to their farming land. Many (60%) are bamboo stilted/very open, located by the maize/paddy fields. Keep Type of animals underneath the house. Others are housing bamboo and CI sheet roofs. Only 3 brick houses in the village. Religion Christian Population, ~200 households. Kodi people ethnicities Main Single crop farming (paddy, maize, cashew) livelihoods One private clinic in the village. Puskesmas, Access to health hospital, pharmacies are in the city (30 mins services 2 hours from the village)

### **SUMBA REMOTE**



Geographical setting	Rural, plains with paddy fields. Big river and a forest nearby.
Type of housing	Majority (60%) are concrete houses with corrugated sheet roof. Others are <i>rumah</i> panggung with wooden floor and wall or bamboo house, and leaves-roof. Keep animals underneath the house.
Religion	Catholic and Christian
Population, ethnicities	380 households/±1,370 people covering 4 sub- villages. Sumba people
Main livelihoods	Farmer
Access to health services	Puskesmas (20 minutes), hospital, private clinics (1 hour motorbike)

### **SUMBA PERI URBAN**



### STUDY FINDINGS

The findings are presented in a way that integrates social determinants affecting malaria interventions, and people's experience of the malaria programmes. This chapter starts with (1) people's behaviour in relation to malaria to discuss how people understand malaria and how they perceive the disease, both from community context and at individual level. The first section also serves as an underlying context for other findings. The following sections are presented in line with the framework of the Government's malaria programmes. Section (2) people's responses to malaria discusses what people do when they get fevers and when and how they access malaria testing. Section (3) experiences of malaria treatment focuses on malaria medication and people's adherence to the treatment. Many of the findings are related to access to malaria services and barriers that the communities encountered in accessing the service. The last two sections are about prevention practices. Section (4) bednets section describes bednets usage and preferences and (5) prevention practices discusses other practices to prevent mosquito bites.

#### 1. PEOPLE'S BEHAVIOUR IN RELATION TO MALARIA

Medicating with herbs

#### 1980s

Active transmigrantion program, new migrants contract malaria with many deaths. Local people less deaths, immunity. Some quinine pills availability

#### 1990s

Quinine pills, puskesmas, testing, freeport program

#### 2000s

Less deaths, less infection, transmigrants know better. Bed nets distribution, spraying. Forests turned into neighborhoods

#### 2007-2008

DHP (blue pills) + primaquine, restricted access with positive test

#### 2010

Different programs on malaria, getting bed nets every year (mid 2010s); Cadre in the village (mid-late 2010s); Malaria kit in puskesmas (mid 2010s); Last known spraying (2017/2018)

#### 2020

Private foundation was established in some areas

When talking about the prevalence of malaria in their neighbourhood, people in the study locations reflected back across time how malaria was experienced in their areas. They recalled the time before the 1980s where malaria was rampant, resulting in deaths. People said they were medicating with herbs and herbal medicines informed by the elders in their community. The 1980s introduced the quinine pills although only some people had access to the medicine. This period also saw the arrival of the transmigrants who contracted malaria soon after they arrived which often resulted in deaths. In contrast, occurrences of malaria deaths among the local populations dropped as they built immunity against the disease.

In the 1990s, the quinine pills became widely available and puskesmas started to be built around their area. Some people remembered that this was the period of time where they first got tested for malaria and in Timika areas, Freeport established a malaria programme to combat the disease. By the 2000s there were less malaria deaths and less malaria

infections, both among the local populations and the transmigrants communities. The transmigrants by that time knew better what to do when contracting malaria. The government started the bed nets distribution programmes and organized some spraying. People also noted to us that this was also the period of time forests area were turned into neighbourhoods, reducing mosquitoes breeding places. In 2007-2008, DHP pills were introduced to the area along with primaquine. The medication was proven to be highly effective although access was restricted and they could only be obtained by receiving a positive result on a malaria test.

By mid 2010s, different malaria programmes were implemented across the study locations, ranging from an NGO trying out fluid mosquito repellants to an Indonesian university conducting malaria mass testing. The communities started to receive bed nets yearly from the government through puskesmas although IRS programmes became less frequent with the last known spraying for malaria said to be in 2017-2018. Malaria testing kits became widely available in puskesmas and in some places, malaria cadres started to work with the community. Towards the end of the 2010s, private foundations aiming to combat malaria were established in some of the study locations.

In the current time, people shared with us that almost everyone has contracted malaria at least once. Children and teenagers told us that they expected to get malaria every year, for some, this might be even as frequent as 5 times a year. On the other hand, adults told us that even though they had contracted malaria before, they rarely did so recently. Mostly recalled being sick when they were younger but infrequently after. Those living in Timika Island estimated they only got malaria once every three years. In Sumba Peri Urban, there were only 80 cases of malaria recorded in one of the puskesmas last year across 11 villages it served. Migrants to the areas shared with us that they did usually contract malaria when they first arrived but rarely contracted it again afterwards.

### People found it difficult to recall any last known death due to malaria in the past 5-10

years. When there was death, it tended to occur due to late treatment. People in Jayapura Forest recalled a baby and a pregnant mother who recently passed because they were late to get treatment. A 5 year old also dies of malaria in Sumba Remote because she was late to be brought to the hospital. Not receiving the right treatment was also fatal to those who were travelling to areas where malaria was less common. People in Timika City remembered one migrant who passed away in Java because his malaria was misdiagnosed as typhoid. Malaria being misdiagnosed as typhoid happened frequently to migrants who visited home (Box story: Self-prescribed malaria treatment).

#### **Self-prescribed malaria treatment**

One Posyandu cadre was a migrant from Central Java who moved to Timika City in the late 1980s. She said that malaria was very common in the area and people "only need to take pills, then done, we're healed. No need to worry too much." She also shared a story when she had malaria symptoms while visiting her hometown for Eid about four years ago. She went to the nearest puskesmas, told the nurse that she came from a high malaria endemic area and had malaria symptoms. They conducted a microscopic test, but the result was negative; they told her she had typhoid although they did not test for it.

The cadre was convinced it was malaria tertiana given its particular symptoms: intermittent fever and less headache. The cadre insisted for a malaria treatment, but the puskesmas' nurse had no idea what to do as she never handled a malaria case before. So, the cadre said to the nurse, "... back in Timika, I hung out with nurses a lot and learned from them about the medication." The nurse then let cadre prescribe the medicines herself: some Dapril (DHP Frimal) based on her weight which was 12 tablets for three days, 14 tablets of Primaquine for 14 days, and Paracetamol.

Field notes, Timika City

#### **PERCEPTION OF MALARIA**

Because malaria was infrequently contracted by adults and death almost never happened due to highly effective medications being available, people in the study areas were not highly concerned about contracting malaria.

Malaria was considered to be common – "biasa" aja" – became normalized. Some people even considered malaria as a friend who they were familiar with. "We and malaria are already friends, becoming one," said the local Papuans in Jayapura Forest. Some people, such as those in Sumba Remote, Jayapura Forest, and Manokwari Urban, did consider the disease to be a serious and potentially dangerous disease because malaria symptoms were considered heavy, "... can't sleep, can't eat, can't get up from bed," (men, 20s, Java), and there was a possibility that malaria could cause brain damage even death. Yet they were not concerned because malaria pills were easily obtained and cured the symptoms quite quickly.

#### Malaria is family

Conversations about malaria with the local Papuans in Manokwari Urban often lead to them telling us that they saw malaria as a part of their life. They mentioned how malaria was in their blood, therefore their friend and even part of the family. "If I could add malaria to my family card, I would," a mother said jokingly. They believed malaria would never disappear from Tanah Papua.

Almost all Papuans have had malaria and most are relaxed about malaria risk or future infection. They believe they know better how to treat malaria through both modern medicines and herbs, compared to non-Papuans.

Field notes, Manokwari Urban

Most people did not think malaria could be eliminated from their area. The Papuan community in Jayapura Forest considered malaria as their inheritance as malaria was passed on from mothers to children through pregnancy and breastfeeding. People in Manokwari Rural saw malaria spanning generations which was impossible to eliminate. Those living in Timika Island said, "... can't go against nature," when talking about the impossibility of eliminating malaria from their environment. One nurse in Timika shared with us that she knew of a target to eliminate malaria by 2026 set by the local Timika government, but she thought that it would be very difficult to achieve. "I think malaria will still be like this for the next 100 years," she told us. Other nurses said to us that they thought that the elimination target needed to be realistic. "... maybe better to aim to make sure people finish the pill," said them.

Compared to malaria, there were other diseases that people in the study locations were more concerned about. Those that had more severe consequences were seen as more concerning. Diseases that often resulted in death such as HIV/AIDS and cancers were feared more. In Sumba Peri Urban, where mouth cancer was rampant, people talked about it constantly, worrying about the disease. Diseases that can't be cured such as filariasis and cancer were more feared as well as those that needed surgery. People were also concerned about diseases that were expensive to treat such as heart disease, hypertension, diabetes or cholesterol.

# Diseases that affected daily lives were also a source of worries for people we talked to.

Those that took a long time to heal, such as tuberculosis (TB), causing long lasting wounds, such as diabetes, or affecting daily activities because inability to walk or breathe, such as uric acid, stroke or TB, were considered to be concerning diseases. People also feared diseases for which they had to take long term medications, such as HIV/AIDS, diabetes, cholesterol or TB, both because long term medication was expensive and because it affected their daily

lives. Some of these long-term diseases were also stigmatized. In Jayapura Lake, people felt ashamed if they contracted TB. Particularly because it could easily spread to others, they worried that they might cause an epidemic in the community and people usually avoided interactions with those who had TB from the fear of contraction.

People told us that they were more concerned about diseases that were transmittable (HIV/AIDS or TB) and those that they did not have much knowledge about or there was not any readily available medicine for (dengue). A mother in Jayapura Forest whose 6 year-old child had had malaria told us that "[With malaria we are] used to getting often. ... Dengue is dangerous because we don't know about [it]. [We're] more afraid of this." People also shared that they were more concerned with diseases that happened frequently such as respiratory diseases, especially when it affected children.

Malaria, on the other hand, was not seen to have severe consequences anymore due to the effectiveness of the medication. It was also quickly and easily cured with infrequent recurrences of the disease. People were familiar with malaria and it no longer affected their daily lives significantly. Malaria was also not considered transmittable by the people we talked to. **Because of all of these reasons, malaria was not seen as a concerning disease by the people in the study locations.** 

#### Who is more vulnerable to malaria?

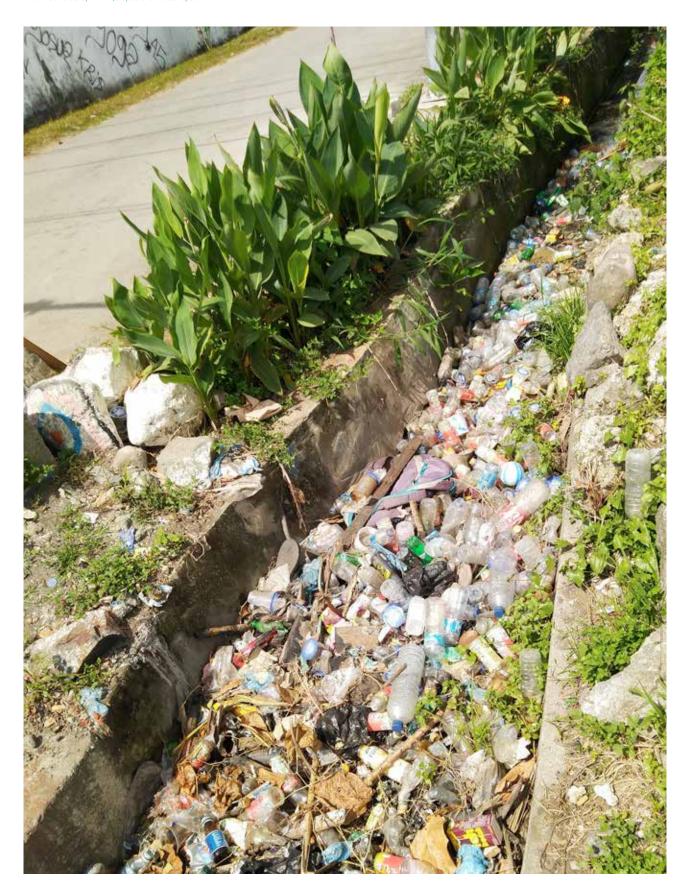
People shared with us who they considered to contract malaria more often than others and who were vulnerable to the disease

 Young children. People said they had a weak or low immune system, "their antibody had not developed well" compared to adults. Children also often played outside shirtless until late, had soft skin and tended to skip meals;

- Teenagers. They moved around a lot to help parents in the garden, hung out outside, and might get mosquito bites at school;
- Babies. They were vulnerable because they could not stand high fever and developed severe symptoms rapidly;
- Pregnant women. They became weaker at early pregnancy and easily got ill. People said malaria was especially harmful for the fetus rather than the women. Some women shared they could not take malaria pills due to their worries that it "will affect the baby";
- Those going to the forest, garden, or staying outside for a long time. In Sumba Peri Urban, women always went to the garden to tend their vegetables;
- Occupations that were tiring or lowering the immune system. People in some work were exposed more to malaria because they did not take care of their health such as construction workers, truck drivers, ojek drivers, forest workers and those who work at the river;
- Those living in houses near bushes or water;
- Newcomers. This was especially in Papua where malaria was considered as an 'introduction' for those who just moved.

#### **KNOWLEDGE OF MALARIA**

People we talked to consider themselves quite knowledgeable about malaria. Most could tell that there were two types of endemic malaria in their area: malaria tropica (caused by *Plasmodium falciparum*) and malaria tertiana (caused by *Plasmodium vivax*). "*Tropica attacks the head and nerve system, tertiana makes your body chill and body pain,*" explained several people in Timika City to us. People were often told by the nurse or doctor when they tested for malaria what type of malaria that they got. Some mentioned to us that they knew that malaria had stages, from 1 to 4 but did not detail what the differences were between the stages.



Clogged sewer and places with a lot of trash were considered to be a cause of malaria because people saw dirty places compromised the immune system.

### Because most people also had had malaria at least once, they could also tell its symptoms.

People referred to high fever that often increased in temperature as one of the signs of malaria. "... in a few hours the body is hotter and becomes hotter and the body is weaker," explained one mother in Jayapura Urban. They also mentioned heavy headaches as one of the common symptoms they experienced. Other symptoms mentioned included shivering, muscle/body pain, feeling weak and vomiting.

Local Papuans shared that they handled malaria symptoms better than the migrants. Even when getting a stage 4 malaria, they still went to work in the field while the migrants needed to take a bed rest. This applied to children as well. One health worker in Manokwari shared with us, "[Papuan children with level 4 malaria] will play soccer while waiting for a test result but incomers at level 1 will not be able to move."

# When it came to what caused malaria, people had a variety of ideas with mosquito bites not being the first thing that came to their mind.

The most commonly mentioned cause of malaria was weak or low immune system. According to the people in the study locations, there were many causes of a low immune system. Being tired or stressed out, lacking sleep or rest and not eating well were some of the common ones mentioned. People also cautioned about getting soaked in the rain or taking bath in the river. This was particularly true for children. Spending a lot of times outside, especially with a bare chest, was also considered to cause the immune system to weaken.

Some people considered drinking a particular type of fluid to lower the immune system as well. Drinking coconut, unclean water and iced drinks were particularly cautioned. People also saw clogged sewers or dirty environments to be bad for the immune system. "Trash impacting your immunity," said a male migrant in Timika City. Certain occupations, such as those who go to the forest or people who fish, were seen to lower the immune system as well due to the job being too tiring or too taxing.

People believed that a strong body could prevent malaria. "Our body should be able to prevent malaria," said people in Jayapura forest. People said they ate well and took enough rest in order to make their body stronger against malaria. They reminded each other to be active because this was seen to help increase the strength of the immune system. Being active also sweated out malaria and for that reason, people also recommended eating hot or spicy food to flush malaria out. "When I work hard the malaria will come out of my pores like sweat," said one man in Timika Island.

#### Who is less vulnerable to malaria?

People shared with us who they considered not that vulnerable to malaria.

- Papuans were considered strong and had different skin. They were knowledgeable and could handle malaria better than migrants because they were used to the disease. Some People and health providers thought that Papuans seemed to not experience malaria as badly as migrants even when they were in the most severe level (level 4). They would still go farming, children would play with their friends, whereas migrants needed to rest in bed as they felt malaria was "ruining your bone".
- Elderly were also thought to be more
  protected from malaria especially if they were
  physically active, as shared by some people
  in Jayapura Forest. Some elderly were also
  driven to protect themselves such as by using
  repellent because they experienced losing their
  children from malaria.

### Other than the immune system, people also blamed the weather as the cause for malaria.

Cold or rainy weather was the most frequently mentioned with a rapid change of weather from cold to warm to cold again being considered equally precarious. Apart from the rainy season, people also said fruit seasons to be the time when malaria was more rampant than usual. They specifically mentioned eating too much fruit as

a cause of malaria as well as that malaria came from the sap of the fruit trees. "Probably from eating the fruit... too much mango," said people in Manokwari Rural when explaining why fruit season caused malaria. Geographical conditions were also seen to be the cause of malaria. Living in a mountainous area, on the coast, or nearby the forest were some of the common features attributed to the cause of malaria. Living in areas with plenty of trees and bushes were also related to the cause of malaria.

Mosquito bites were only the fifth common causes that people referred to as the cause for malaria. People in Manokwari Rural, Timika Island and Sumba Remote were the ones who often mentioned mosquito bites. People did tell us that they were aware that some mosquitos brought diseases while others did not and some people linked places with higher prevalence of mosquitos to catching malaria. Although, those who were aware that mosquitoes were a vector of malaria usually did not know the reason why. Some people told us that they did not believe that mosquitoes caused malaria. "I don't think malaria is caused by mosquitoes, because people might get bitten but don't get fever, but if you get soaked at night, you'll get malaria in the morning," explained one Javanese migrant in Timika City. Some reasoned that people in Sulawesi sometimes got malaria too and to them it did not make sense that the mosquitoes could travel that far. "People don't take the mosquitoes with them," said people in Jayapura Forest. Some other causes for malaria that people shared with use were being passed on from mothers through pregnancy or breastfeeding, that malaria already existed in one's body, either in the spleen, inside the heart or in the blood, and that malaria was caused by the necessity to adapt to a new environment. This last one was particularly true for migrants.

We also talked to health providers about the cause of malaria. People's knowledge of malaria is often similar to the knowledge the health providers communicated to them. Although most did mention mosquitoes to be the main cause, some did share with us other causes of malaria. A weak immune system was one that they mentioned often. The nurse who was in charge of the malaria programme in Manokwari Rural said, "Once bitten you will get it again if you eat irregularly, the immune system is low and [you] don't sleep under bed net." The cadres in Sumba Peri Urban cautioned against drinking uncooked water as it made the body weak, causing dormant malaria to resurface.

A doctor in Manokwari Urban said that she did tends to ask about eating habits and environmental hygiene when consulting a malaria patient rather than talking about mosquitoes. "People won't realize it when they got bitten," he explained so he reminded them more about eating well and to maintain their immune system.

One nursing student who recently graduated from studying in Java came back to work in Manokwari. She told us that she did not receive any lessons on malaria when she was at school so she had to study about it herself. Similarly, migrants who came to the area had no previous knowledge of malaria before they arrived and often had to rely on local people on what to do when contracting malaria. "I moved here, I had high fever but didn't check with doctor. I asked the locals and followed their instructions on what to do," said one migrant man in Manokwari Urban.

One cadre in Timika City could not relate mosquitoes breeding in puddles of water with malaria. She said, "In Java, puddles cause dengue". To her mosquitoes could only cause one disease and not another.

People we talked with had the least knowledge about malaria transmission. Very small numbers of people across all study locations who specifically mentioned plasmodium transmission from person to person facilitated by mosquitoes. One of them, a mother from Timika Island, recalled that she learned about it in school while the other two were not sure how they came about the information. Health providers themselves often did not know how malaria transmission

could occur and people told us that malaria was non-transmittable, unlike HIV/AIDS which they considered more dangerous because of that reason.

Our observations found there was little information about malaria available for the public. Printed media were found only in some locations. Puskesmas in Timika Island and Manokwari Urban had posters about malaria, whereas an NGO's building in Timika City had a banner. Other health information (COVID-19, pregnancy, TB, HIV/AIDS) were more commonly found at the puskesmas. However, people did not seem to notice them. Cadres in Jayapura Lake used to have information show cards that they used to talk about malaria with community members. The cadres received them from a training and found them to have eye-catching information, but all were gone due to flood. Only in Timika City we found an information session on malaria was targeted at school students, which was done in collaboration with puskesmas.

People also shared that information on malaria for pregnant women was minimum. Posyandu distributed bed nets and told people how to use and treat them, but did not give information on malaria. ANC sessions did not provide specific information about the disease except for Timika Island where the midwives said they told pregnant women to use bed nets and to be careful with mosquitoes. However, they were not actively promoting this if they saw the women were healthy.

Only in Manokwari Rural did pregnant women get malaria screening during pregnancy. This was done along with screening for other communicable diseases (hepatitis, syphilis and HIV/AIDS), as a midwife explained, but health staff did not seem to explain this to the women. However, some women in Manokwari Rural and Timika City said they were only tested for malaria when they experienced malaria symptoms.

Some people mentioned they received information about malaria from direct

communication with health staff when they sought treatment. The private foundation clinic staff in Sumba Remote allocated time to explain malaria to people who came for malaria testing and treatment and answered their questions. People also regarded the staff as friendly and non-judgmental. A food vendor in Manokwari Urban said Puskesmas staff used to give socialisation about malaria to food vendors in the city but he did not remember what they said and the Puskesmas staff did not leave any communications materials behind. In Sumba Remote, a Puskesmas Staff told them about herb plants they could consume along with malaria medicines.

Across all locations, people preferred personal contact and trusted local sources as their source of information. News was distributed through word of mouth and people usually got information from local trusted sources such as nurses/health staff or people who visited the city. People did not have much engagement with mass media (TV, radio) or social media (Facebook, WhatsApp) to get information. Some people had smartphones, and those who had one tended to use them for entertainment (watching videos, listening to music or social media for youth) and did not use them to access information.

# KNOWLEDGE AND PERCEPTION OF MOSQUITOES

Despite not immediately linking mosquitoes to malaria, people were very aware of the presence and prevalence of mosquitoes. They told us when they noticed that mosquitoes tended to be more active. People mentioned times when it was dark outside or when no sun was present to be when mosquitoes were usually around. During the afternoon, evenings, as well as the time slightly before dusk and a few hours after dawn were the period of time people told us when they noticed more mosquitoes were present. People also frequently noted that rainy seasons as well as fruit seasons to be the season of mosquitoes.

Although some people noted that despite some time or season brought more mosquitoes, they noticed that mosquitoes were always there. People in Sumba Peri Urban said to us, "Mosquitoes don't know hours. Whenever they want to bite, they bite." They also noted that in some areas, such as in the garden and in the forest, mosquitoes were always abundant despite the time of day.

### People were also very familiar with where mosquitoes were more prevalent in their

areas. They mentioned puddles, fields, garden, bushes, forest, river, swamp, and the beach areas to be where they noticed a lot of mosquitoes. Places they considered dirty such as areas where there were a lot of trash or used alcohol bottles laying around, places with clogged sewer, as well toilet areas were also noted as places with plenty mosquitoes. People likewise mentioned animal cages, animal dungs, where cows were, as well as cows' footprints that turned into a puddle to be often riddled with mosquitoes.

Flooded areas were also pointed to us to be where mosquitoes were rampant (Box story: Clogged drainage system) and in Timika Island where they often experienced flooding due to frequent rain, under the house and under the wooden walkways where mosquitoes were often found. Inside the house, people told us that dark corners as well as places where there was no light as rife with mosquitoes. People who lived in wooden houses which often had gaps on walls and floors had to deal with mosquitoes more often except in Sumba Peri Urban where the wind was strong which entered the wooden house through the gaps and blew mosquitoes away.

#### Clogged drainage system

The Timika City area changed in the 1980s due to the transmigration programme when the government of Timika cleared the forest and distributed the land to migrant families. The housing area was designed in a grid of five alleys, each hosted different groups of community. Years later, some people converted their houses into *kontrakan* (rented rooms) for seasonal migrants coming to the area.

The landscape change had caused severe flood. An elderly migrant said, "There was a river passing through this area before, but as development continues, we can't see the river anymore." After a heavy rain, he would have to clean the house from mud. He also noticed mosquito larvae when floodings happened.

Government constructed drainage to resolve this problem but people felt the project was all over the place. The government did not measure the different heights of the alleys and there was no proper maintenance of the drainage. The drainage was clogged with trash which in turn led to flooding in the area. One mother, whose parents migrated in 1982, even said that they never experienced flooding before the drainage was built.

The Village Head shared a different view about the situation. He thought the heads of RT (neighbourhood unit) were responsible for sewer cleaning and he had ordered them to do *Jumat Bersih* (Friday's voluntary cleaning). However, the community was not taken to the idea. One man shared with us that no one wanted to do voluntary work because there was no pay.

Field notes, Timika City



Area in Jayapura Forest where there were a lot mosquitoes due to open defecation toilets and where pigs and cows roamed.

When discussing where mosquitoes were in their neighbourhood people also told us where they considered there were no mosquitoes. Inside brick houses were often mentioned and inside the house in general compared to being outside were said to be where there were no mosquitoes. However, in these places we observed there were still mosquitoes around even though it was only one or two and not as many as it was in places where mosquitoes tended to gather. It is then important to note that people tended to use the phrase 'no mosquitoes' to mean that there were not as many mosquitoes in that place compared to other places and NOT that there were no mosquitoes at all being around.

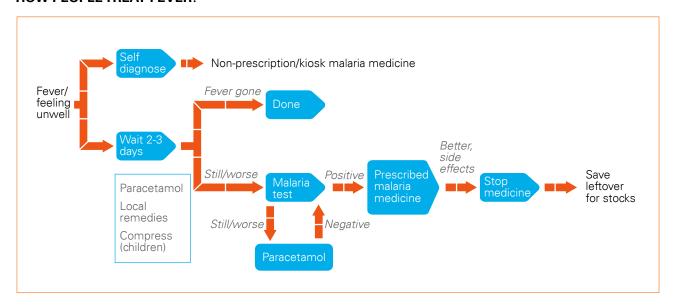
Some people told us that they could tell the differences between malaria mosquitoes and other mosquitoes. Size was one of the characteristics people mentioned although some told us that malaria mosquitoes were bigger than other mosquitoes while some said they were smaller. People also shared that the bite of the mosquito was more painful. "It hurts more because it's like a small injection," said people in Manokwari Urban. They said the malaria mosquitoes had long rear and they stuck their bottom up when biting. Some people said the colour of the mosquitoes were black while others noted that the legs usually had white dots or stripes. People in Manokwari Rural told us that when you managed to swat a malaria mosquito, there was no blood coming out of the body.

However, some people could not really tell what differentiated malaria mosquitoes from other types of mosquito. This was particularly in places such as Sumba Peri Urban where other diseases caused by mosquitoes, such as dengue or filariasis, were also rampant. People were not sure which mosquitoes caused which disease.

People told us that they found mosquitoes a nuisance but they put up with them, especially when they were working as they focused more on the activities at hand. "You see the cashews ready for harvest, then forget about the mosquitoes, all you see is the money," said people in Sumba Remote to us. People were particularly annoyed when mosquitoes disturbed their sleep but they did not really talk about being unhappy with mosquitoes because they were linked to malaria.

#### 2. PEOPLE'S RESPONSES TO MALARIA

#### **HOW PEOPLETREAT FEVER?**



Most people were aware of fever as the main malaria symptom. Across all study locations, people would self-diagnose or wait and observe their fever for a few days before deciding to visit health providers. Those who self-diagnosed assumed having a fever meant they were having malaria. They would then self-medicate either by consuming non-prescription medicines they bought themselves from kiosks or local pharmacies. People usually took the medicines until feeling better or until the fever has gone.

People who adopted the wait and see approach usually waited for two to three days, some up to one week, before seeking medical care.

In the meantime, they took paracetamols and/ or used local remedies to treat their fever and headache. Herb remedies were particularly popular among Papuans. People shared with us their stories of consuming bitter plants to cure fever or to support their immune system. They ate or boiled certain parts of the plants such as the leaves (sambiloto, papaya, kumis kucing, bitter melon, kelor (moringa), meniran, itchy leaves,

yellow, awok, afrika, gamal, *jambu biji*, etc.), root, sap, flowers, bark, or fruits (solanacea berries, mahogany roots, ello tree bark, *langsat*, etc.). Another technique was called *ungkup* where people boiled the leaves then covered themselves with a blanket over the steam to induce sweat.



Meniran leaves and kumis kucing (Orthosiphon Aristatus), herbal medicinal plants often used across study locations.





















Plants that people used to treat malaria symptoms (fever and headache)

- (1) Sambiloto leaves
- (2) Almost all people in the neighbourhood have plants to cure malaria, such as these papaya leaves.
- (3) Itchy leaves
- (4) Soursop, guava, noni and jarak leaves. An elderly said they use them when feverish and help to relieve discomfort from malaria infection
- (5) Sambiloto tree
- (6) Africa tree's leaf and klorofil leaf
- (7) Sambiloto tree
- (8) The military army showed us these woods, given by the locals who said it could prevent malaria
- (9) Malaria wood from the forest to treat 'biji malaria' (dirty blood in the stomach after someone suffers from malaria)
- (10) Ello tree. Water boiled with the tree bark to cure malaria
- (11) Mengkudu (Morinda citrifolia) leaves

The next action depended on how the fever developed. If it disappeared, people would stop the treatment they had. However, if the fever remained or became worse and included other symptoms such as shivering or horrible headache, they would visit health providers to test for malaria. In some cases, people with negative results still experienced symptoms even after taking more paracetamol. They would then take one or several more malaria tests until they received a positive test result in order to get malaria medication to treat their persistent fever.

People with positive results were given malaria medication from the health providers. People told us that they usually stopped taking the malaria medicines as soon as they felt better or when the fever was gone. Any leftover pills would be stored for stocks in case they or a family member contract malaria again in the future.

People who waited on their fever told us that they have different reasons for doing so. Parents said that children had fever all the time and the cause was not always malaria. So, they waited to see if the fever would just go down on its own. Men thought fever could be treated with local herbs or that they could simply sweat it out. They tended to visit health providers when they felt really sick. Men and elderlies in Jayapura Lake, for instance, believed in herbs they had been using to treat fever and were hesitant to rest and take medicines. People also told us that they waited for a few days before going to health providers to check their fever because they were advised to do so by health providers. The health providers reasoned that the fever might be caused by a virus and it took several days before the virus could be detected.

The only exception was in Sumba Remote.

There, people immediately visited the private foundation clinic on the first day of getting a fever and were tested for malaria. If the

test resulted positive, they would receive free treatment and malaria medications. Otherwise, they would pay IDR 5,000, similar to the puskesmas' policy if one was not registered with BPJS (national health insurance). The clinic gave 10-days malaria medications and asked people to come back for a retest after they were done with the medication. The clinic did this to minimize malaria transmission. People told us they did come back because they wanted to make sure that they were healed.

People in Sumba Remote shared with us that this was not the case before the private foundation clinic was established as they used to delay seeking treatment even for children. If a child fell ill, they would use local remedies or give the child medicines bought from kiosks. It was only on day three of having a fever that parents would bring their children to the puskesmas. They told us that they delayed going to the puskesmas because they reasoned that children could be feverish simply because they were playing outside for too long. It was also expensive to go to the puskesmas as it was located an hour motorbike away and people did not own their own motorbike. People also delayed because they thought the amount of malaria in the body might be too small for the puskesmas to find before day three.

#### **TESTING FOR MALARIA**

When people did decide to test for malaria, they would rather go to a provider they trust such as a malaria cadre or a doctor practice. People also preferred to go to a provider that was nearby or places where treatment did not incur them cost. They also preferred places with a short queue and a quick process. Those who could afford it might visit better services, usually a private clinic or a hospital. In Timika City, some people got tested during IRS spraying (Box story: Mobile malaria test).

#### Mobile malaria test

A mother in Timika City goes to work everyday as a household assistant. When we met her, she did not work because her son had a fever since the night before. She was about to take her son to the puskesmas when she heard about a malaria spraying in her area from the MalCon team. This meant there would also be a free malaria test. She decided to wait for the malaria team to visit her area.

The malaria team arrived with a car parked about 50 meters from her house. She took her child for the malaria test. After collecting blood samples, the team took them to the puskesmas and said they would come back if there was any positive case. Around noon, the malaria team came to the mother's house and she quickly approached them. They said her son had malaria tropica, handed her the medicine and explained in a hurry, "Ma'am, there are three plastics, take one plastic with yellow medicine and blue medicine for today, then take a plastic containing blue medicine for tomorrow at the same hour. Finally, take a plastic with blue medicine for the day after tomorrow at the same hour. There is a fever medicine, take three times a day until the fever is gone and vitamins are taken once a day. Do you understand?" The mother just nodded at the staff's explanation. The staff then returned to his friends who waited in a car and left without further explanation.

Field notes, Timika City.



A child in Timka City being tested for malaria through mobile malaria test coinciding with IRS done by MalCon.

There were some challenges that people told us regarding malaria testing. People said they sometimes received unexpected malaria test results; they were tested negative for malaria but continued to have the symptoms. When this was the case people would take another test usually at another health provider due to their concern that the previous negative test was not accurate. A mother in Timika City said she took her daughter for a malaria test at the puskesmas and the test came out negative. Because her daughter still had a fever, she took her to a private clinic the next day for another malaria test which came out positive. A similar story happened to a child and an elderly woman in Timika Island. Both tested negative, but their symptoms remained, so they wanted the test to be repeated (Box story: Insisting for RDT).

#### **Insisting on RDT**

An elderly woman in Timika Island said to us as we were walking to the puskesmas, "I have a malaria tulang (bone malaria), my bones hurt and I want to get the pills". At the puskesmas, she asked for an RDT and tested negative. The woman insisted that she had malaria. The nurse however could not give her malaria pills and asked her to come back in three days for a re-test.

There, we also met a father with his nine yearold son who he said had malaria. The boy's malaria test came out negative. The nurse gave him paracetamol and asked them to come back the next day if the fever remained. Later that day, the nurse told us that people knew when they had malaria even before being tested and would ask for the malaria pills. She could not give them the pills if the test was negative but people insisted about having malaria, so she usually asked them to come back for a re-test in one or two days.

We visited the father and his son the next day. The son continued to have a fever, so they went to a nurse at her house for a re-test and still the test came out negative. "Sometimes the RDT is not precise," said the nurse. They were thinking of going to the city for a retest but decided to try again at the puskesmas. They asked for a retest on one left finger and then on one right finger. One of those tests came back positive. The boy then took the malaria pills and was already playing with his friends that afternoon. The father told us he knew that his son had malaria since the beginning and therefore he insisted on having the pills.

Back from the father and son's house, we passed the elderly woman who said she had bone malaria. We asked where she was going to which she answered, "My bones still hurt, I am going to the nurse's house to get malaria pills!"

Field notes, Timika Island

People told us that they were aware that the rapid test (RDT) did not always provide accurate malaria assessment compared to a microscopic test. **Yet, for some people, such as those in Jayapura Lake, only RDTs were available** due to the distance to medical establishments or because the health providers did not have the resources to do a microscopic test.

False negative tests could also result from taking medication before the test. People in some locations learned that when they took paracetamol the night before the test, their test result would come out negative. Their subsequent test result would then turn positive after stopping the medication (Box story: 'Hidden' malaria).

#### 'Hidden' malaria

A male driver in Timika City said to us that he recently got malaria, "I went to puskesmas but tested negative. I knew I got malaria but only get paracetamol. After two days, I went back to puskesmas – this time the test showed I got malaria tropica." The driver then asked the nurse why the first test did not show malaria. "She told me if I took paracetamol the night before, the malaria might be hidden so I should not take any medicine before the test," he recounted.

One mother also told a similar story about her husband to us. Her husband took paracetamol when he had a fever. The next morning, they went to the puskesmas for a malaria test. The husband received a negative result but his fever remained. He was in much pain, so they went to a private clinic. There, he tested positive and received medications. Since then, he never tested for malaria in the puskesmas again and preferred the clinic.

Field notes, Timika City.



Malaria medicines common in the study locations: primaquine (yellow tablets) and DHP (blue tablets).

# 3. EXPERIENCES OF MALARIA TREATMENT

#### **MALARIA MEDICINES**

In all locations, malaria was mostly treated with oral medicines which typically included DHP and primaquine. People were usually given three tablets of DHP per day for three days and one primaquine tablet per day for one day to treat malaria tropica or for 14 days to treat malaria tertiana. The dosage for children was adjusted to their age and weight. Access to malaria pills was restricted and only those who provided positive test results could receive the pills. Although some patients in Timika Island were given less pills than suggested by the puskesmas. They only received one primaquine pill for malaria tertiana because the puskesmas did not have enough primaquine pills to cover all 14 days of treatment.

Other than DHP and primaquine, other malaria medicines such as suldox, quinine and chloroquine were also available in some study locations. As for chloroquine, a pharmacy staff in Manokwari Urban explained that the pills nowadays only worked to treat malaria for migrants, but they no longer worked for local Papuans. People said these pills were easily accessible at clinics, pharmacies or kiosks and they could be bought

without prescription. The pills were usually consumed alongside some other medicines to treat the different symptoms such as paracetamol for fever, antalgin for headache and vitamins to boost the immune system.

#### **Malaria medicine for COVID-19**

A local pharmacist in Manokwari Urban recounted the time nearing the start of the pandemic when people heard the rumour that Chloroquine—which was widely known and used in the area as a malaria treatment—could cure COVID-19. Many then bought Chloroquine from the pharmacy which can be obtained without prescription. Because of the increased demand, the pharmacy applied a new rule that one person could only buy malaria drugs including Chloroquine and Primaquine, if they had positive malaria test results.

Field notes, Manokwari Urban

Most people taking malaria pills said they would only take them until feeling better, thinking that it indicated that their malaria was

**gone.** This could be as early as after a day or even after taking just one round of medication. Rarely did they finish the malaria pills given to them, particularly the primaquine when given for 14 days. People also stopped taking malaria pills due to them experiencing the side effects.

Some people said that they did not receive specific instruction to complete the medicines while some others said they did receive some advice from the health providers. Although most people knew that they should take all three DHP pills at the same time. The DHP pills were referred to as 'obat keras' (very strong medicines) that would make them feel better quickly if taken correctly and not spread out throughout the day. People in Timika City were aware of the consequences of not finishing malaria medication. They told us, "if you do not finish the yellow one, malaria can be repeated". Yet, not everyone complied including a nurse there and a different one in Manokwari Urban, both did not finish their treatment for malaria tertiana (Box story: Recurring Malaria).

#### **Recurring malaria**

A young man (19 year-old) said to us, "Malaria is my friend," as he contracted malaria three to six times a year. Many people in Timika City said something similar, "Malaria is like my favourite warung nasi [eating place], I come back again and again".

A nurse and a malaria cadre in the area shared a similar sentiment. The cadre had malaria three times last year with two weeks difference between the first and the second infection. He said it was likely because he did not finish the 14-days primaquine for the first malaria (malaria tertiana). "It's too long, I often forget especially when fever already gone."

The nurse had malaria tertiana (plasmodium vivax) then, after a year, she contracted malaria tropica (plasmodium falciparum). She concurred that many people did not complete their medication especially in the malaria tertiana cases. She herself once did not finish all the pills because of the aftertaste of the primaquine pills. The second time she contracted malaria tertiana, the nurse set an alarm and had her colleague remind her every day to take the pills.

Field notes, Timika City

Men tended *not* to finish medicines more frequently compared to women. Some children and teenagers did finish their medications especially if their mothers monitored them. Teenagers in Jayapura Lake who were not supervised by their mothers usually stopped taking the medicines after a day or two as they felt better. one mother there said to us that teenagers "can no longer be told what to do. They decide themselves when they will take the medicines".

#### Home visit by nurses

During a lunch break, two nurses in Timika Island looked ready to go somewhere in a casual outfit. They told us that they were about to see a patient in Village 1, located about 1 Km away and it was only accessible by walking.

One of the nurses shared later that day that in Village 1 they talked to a mother whose 8 year-old boy contracted malaria tertiana with a positive RDT test from the puskesmas 11 days before. The nurses asked whether the boy had finished his prescribed malaria pills. The mother answered there were two blue pills and 13 primaquines left. "The boy only took one day dosage and his mom did not monitor his treatment. No wonder he got sick again," explained one of the nurses to us. The nurses did not prescribe any new dosage and told the mother to make sure that her son finished the pills that had been given.

The nurses then decided to visit the house again after office hours. They were worried that the mother did not understand their instruction, so they went there to give more explanation and made sure she understood.

Field notes, Timika Island

People also shared their experiences of **side effects when taking malaria medicines. These included buzzing ears, loss of hearing, nausea, vomiting due to the taste of the pill being very bitter, severe headache, and drowsiness.** One
man in Timika City complained of severe headache
from the malaria pills that he felt like he "... would
die if I finished the pills". As people started to feel
better in their recovery from malaria, they started
to notice the side effects more and decided not to
complete the treatment because of it.

Due to its strong effect, some told us that the malaria medicines might be dangerous for pregnant women. A woman in her early 30s recently went through a miscarriage after taking malaria pills. "It's a strong pill and she did not know that she was at an early stage of pregnancy," a health provider in Timika City explained. A cadre in Timika Island shared the same view of the medicine's effect on pregnancy and told us that some unmarried girls used the blue pills to induce abortion.

Some people shared with us that they felt tired and had had enough of malaria pills so they switched to something else such as local herbs to treat their malaria. One migrant construction worker shared with us that he had contracted malaria several times. The last time he contracted it around a couple years ago, he became angry with the usual medications he had to take and decided to take 36 suldox tablets over a period of 2 weeks instead. He bought the tablets from the city and they cost him IDR 190,000 for 60 tablets.

### People also said they stopped the medicine because they thought it did not work. Some

Papuan adults and teenagers in Manokwari
Urban said that people usually had their preferred
medicines, the one that worked best for them. If
the medicine did not work, then that medicine did
not suit them and they would try other types. If
it worked, people would take the same pills the
next time they contracted malaria. Some others
thought injection was better than pills as it fasttrack the medicines. Those who were not afraid of
needles would rather have injection than pills.

#### Health providers sometimes asked people to come back to retest for malaria after the medication was complete, but they could not

follow this up. Sumba Remote location was an exception to this as most people did come back to the private foundation clinic to retest for malaria when they completed all the pills. Similarly, some people in Sumba Peri Urban came back to puskesmas following the puskesmas' strategy. They gave malaria pills for every three days, then asked patients to come back for retesting. This way they ensured people completed their treatment although not everyone followed these instructions because they felt better earlier than three days. One mother in Sumba Peri Urban shared that she did come back after three days and stopped taking medicines afterwards because "there was no more malaria".

### PEOPLE'S DECISION MAKING IN TREATING MALARIA

In a household, mothers usually took the health decision making role and they were more cautious about their young children's

health. Mothers in Sumba Remote, Jayapura Lake and Manokwari Urban would promptly take their young children, usually under five years of age, to the health providers when they were feverish. Mothers in Jayapura Lake shared that they paid more attention to younger children when they were feverish because they could get really sick while older children and adults could manage themselves. Although first time mothers usually were less knowledgeable on what to do and would seek help from their Mama Tua (the older sister of their mothers). Mothers across all study locations would also monitor children's symptoms, gave the children paracetamol if deemed necessary and tried home remedies such as cooling down their children's forehead with water, often infused with herbal or medicinal plants. If the children did not get better, mothers took them to clinics, puskesmas or to a cadre to be tested for malaria.

Even though parents pay more attention to the younger children's health, teenagers usually told their mothers when feeling unwell and followed what they were told to do although teenage boys often only shared this when they found pain and other symptoms 'unbearable'.

Teens in Timika City told us that they would look to their mothers to make health decisions because their fathers were often busy with work. Teenagers depended on their mothers to take care of them including taking them to health providers. Sometimes, fathers would also accompany them, especially when travelling was required such as in Sumba Peri Urban where the puskesmas was located around 1 hour motorbike ride from the village. Only in Sumba Remote where we found teenagers willing to go to the private foundation clinic themselves when they experienced a thumping headache.

### Adult men tended to delay treatment and asked their spouse to get medicines for them.

Women said it was difficult to get their husbands to take care of themselves. Men would treat

themselves with herbs or kiosk medicines or leftover malaria medicines if they had some. Those in Jayapura Forest and Jayapura Lake would ask their wives to get malaria medicines from the malaria cadres if they suspected they had malaria.

This meant men often self-diagnosed and consumed malaria medicines without getting tested. Men usually would only go to health providers when they were really sick. Women in Jayapura Forest told us they would sometimes have to push their husbands to seek treatment. Overall, women were the ones responsible for health decision making in the family and were able to go on their own or took their children with them to seek health care. It was only in some cases in Sumba Peri Urban where women had to wait for their husbands to return from farming to bring them to the puskesmas. This was due to the puskesmas being 1 hour motorbike ride away from the village.

**Table 3:** Ranking of where people said they would go when seeking malaria diagnosis and treatment

Manokwari Urban	Manokwari Rural
<ol> <li>Self-diagnosis</li> <li>Private clinic/hospital</li> <li>Pharmacy</li> <li>Puskesmas</li> </ol>	<ol> <li>Puskesmas</li> <li>Private clinic in the city.</li> </ol>
Jayapura Forest	Jayapura Lake
<ol> <li>Private clinic         <ul> <li>(migrant) and cadre</li> <li>(Papuan)</li> </ul> </li> <li>Puskesmas</li> <li>Drugstore (migrant) and private clinic         <ul> <li>(Papuan)</li> </ul> </li> </ol>	<ol> <li>Cadre</li> <li>Puskesmas at the city</li> <li>Private clinic / hospital</li> <li>Subdistrict puskesmas</li> </ol>
Timika City	Timika Island
<ol> <li>Self-diagnosis</li> <li>Puskesmas</li> <li>Private hospital</li> <li>Private clini</li> </ol>	<ol> <li>Self-diagnosis</li> <li>Puskesmas</li> <li>Midwife/ nurse's house</li> <li>Hospital</li> </ol>
Sumba Remote	Sumba Peri Urban
<ol> <li>Private clinic</li> <li>Puskesmas</li> <li>Private hospital</li> </ol>	<ol> <li>Puskesmas</li> <li>Public hospital</li> <li>Private clinic</li> </ol>

#### **ACCESSING MALARIA SERVICES**

For most people, puskesmas was their main service provider when seeking malaria tests and care, even if puskesmas was not their first preference in health service providers. This is partly because people in most study locations could easily access the puskesmas in their village or ones located nearby.

The exceptions were those who lived in Jayapura Lake, Sumba Remote and Sumba Peri Urban where the puskesmas were located some distance away from their village and people had to pay for public transportation fee or motorbike/car rent to go there. We also found some puskesmas were overstaffed. Manokwari Rural had 30 staff of which only 7 were actively working while the puskesmas in Timika Island had 70 staff serving a community of 2,000. The ongoing COVID-19 pandemic by the time of the research also affected puskesmas. Sumba Remote's puskesmas was currently closed because a doctor and a nurse were infected with COVID-19. For a similar reason, Manokwari Rural's puskesmas was closed for three days whereas the laboratory staff in Sumba Peri Urban's puskesmas was seconded to a COVID-19 clinic.

Some puskesmas did not have staff who were able to conduct microscopic tests. Some staff shared with us that they did not want to learn to do the microscopic test even though they were aware that it provided a more accurate result for malaria screening than RDT. The health providers shared with us that using the microscope was tiring because they had to stare at the sample for 10 minutes. "It hurts the eyes. There's no insurance for our eyes even though the result is more valid," said a health provider in Manokwari Urban. The health provider in Timika City similarly said, "My eyes hurt because 20-60 people getting tested [everyday]." Timika City's puskesmas staff also shared with us that they increased the liquid concentration used for microscopic tests from 3% to 15%.10 This was done to quicken the straining

<sup>&</sup>lt;sup>10</sup> The national standard for malaria microscopic test requires the use of 3% liquid concentration for 45 minutes straining time. In some cases, health staff may increase the liquid concentration (e.g. 15%) for a shorter straining time (10-15 minutes).

time in order to be able to get the malaria test result on the same day as demanded by the patients (Box Story: Reduced reagent for faster testing).

#### Reduced reagent for faster testing

One puskesmas in Timika City could perform up to 50 microscopic tests in half a day. The nurse said they were very busy because people wanted to get quick results while they only had a limited number of laboratory analysts.

To obtain quicker results, the analyst used 15% liquid concentration instead of the national standard of 3% needed for a malaria blood test. "[With] less reagent, [it's] quicker to dry ... But actually less parasite can be identified so it may result in false negative," said her. Hearing what she said, the head of the puskesmas nodded, "What can we do? Everyone wants to get it fast." With this practice, the puskesmas managed to test 900 – 1,200 positive cases per month among a population of 14,000.

Field notes, Timika City

Puskesmas staff also shared with us their challenges and effort to manage limited medical supplies. Staff in Timika Island and Sumba Peri Urban said they had to restrict the number of malaria tests and malaria pills to make sure their stock lasted. "We have to limit this," a nurse in Timika Island said referring to the malaria test. She said they did so out of concerns that due to the high demand of tests, up to 10 tests a day, they would run out of supply before it was time for restocking. They could borrow supplies from other puskesmas which they needed to return upon restocking, lowering the number of stocks they had for that given period of time. The puskesmas staff also had to carefully report the number of pills and some adjusted the number to justify their report. They would restock every three months and could only request for an additional 10% of the supplies from the amount

they received recently. In Sumba Peri Urban, the health providers washed the old negative slides and reused them to stretch the availability of malaria tests. Otherwise, they had to file a request to the *Dinas Kesehatan* (local health office) or, if available, they borrowed slides from other puskesmas.

People told us that they were often dissatisfied with puskesmas' service. They shared with us that some puskesmas did not have the adequate technology, supplies or trained staff to conduct accurate microscopic tests. In Sumba Remote, people told us that the nearest puskesmas sometimes told them that they were not infected by malaria, but the private clinic's test result showed that they were. People in Timika City, Manokwari Urban and Timika Island also said they had received inaccurate or false negative malaria tests from puskesmas. At the time of our visit, the puskesmas' laboratory in Timika Island



Long queue at Timika City's puskesmas for malaria test.

was empty and did not have any analyst since August 2020. Similarly, puskesmas in Manokwari Rural had microscopic tests available since 2014 but there was no laboratory analyst assigned to do the test, so they continued to use RDT. A woman there also said she did not like visiting the puskesmas because their "medicines are not complete" referring to both malaria treatment and RDT.

People were also dissatisfied with puskesmas' service because it tended to be slow and there was often a long queue especially among communities in Jayapura Forest, Timika City and Manokwari Urban. A mother that we met at a puskesmas in Timika City recalled the time when she arrived at 6 am to collect her queue ticket. She received number two in the queue but was only seen at 11 am. Others also shared that medicines from puskesmas were not working for them and the puskesmas' equipment were often not complete. The repeating false negative results of malaria tests from puskesmas further eroded people's trust in the establishment.

Some people in Manokwari Rural and Sumba Peri Urban said they could not rely on the puskesmas and that they provided low quality service. People in Sumba Peri Urban noted how the puskesmas kept giving them the same medicine despite the illness. Moreover, the doctors kept their distance and did not physically examine the patient since the COVID-19 pandemic, which some people did not like. In both locations, people preferred going to private clinics or pharmacies. In Jayapura Forest, the puskesmas did not provide service outside of operating hours which made it difficult for some people seeking health care there.

In Jayapura Forest, Sumba Peri Urban and Timika Island, people mentioned that puskesmas' staff were unfriendly. Some staff in Jayapura Forest refused after-hours treatment and were grumpy, whereas some doctors in Sumba Peri Urban were ignorant, patronizing to patients, and made it difficult for patients to get a referral (Box story: good doctor, ignorant doctor).

#### Good doctor, ignorant doctor

One of the mothers in Sumba Peri Urban told us that "... there's a good doctor and an ignorant doctor but you can't choose because puskesmas choose for you". She explained, "the ignorant doctor doesn't ask, only do an exam, the nicer doctor will talk to you, explain to you. If you get ignorant doctor it's not a happy experience". She said that if they happened to be seen by what she called an ignorant doctor, they were likely not going to get better because the doctor did not do a thorough examination on them. But she said that they would still take the medicine given by that doctor anyway because they felt they did not have a choice.

Field notes, Sumba Peri Urban

Despite the above, people, such as those in Sumba Remote and in Timika City, still accessed puskesmas' services for non-malaria illness and because it was affordable especially for migrants. People also visited to get BPJS referral for treatment at the hospital. Although some people, such as those in Sumba Peri Urban, told us that they would only go to the puskesmas or the public hospital "if we are already dying". People in Sumba Peri Urban would rather visit private clinics. They told us that they preferred injections than oral medication and often could only receive this in clinics or hospitals. They also said that the medicines they received from puskesmas often did not 'suit' them as they were not getting better after taking them (Box Story: Puskesmas is not a preferred health provider).

#### Puskesmas is not a preferred health provider

One family shared with us their story about the puskesmas in Sumba Peri Urban. Both the mother and the father said they really did not like going to the puskesmas. They preferred the private foundation clinic even though the clinic was far from the village. They said that puskesmas always gave them paracetamol, mefenamic acid or amoxicillin, no matter the illness, and those medicines were not working. Some other families shared a similar sentiment. They said, "If the medicine from puskesmas 'suits' you, then you will get better". Otherwise, they will go to another clinic to find a medicine that "suits you better". Another family said that the puskesmas no longer gave medicine through injection, so they had to go to the clinic for it. They considered medicine given through injection as more potent than tablets or pills.

Another father shared that he thought that the puskesmas sometimes refused to give better medicine. They would prescribe paracetamol and tell patients to come back if the fever did not get better after three days. The father then said, "We want to get better right away, how come they told us to wait for 3 days?" He too preferred going to the pharmacy or the private clinic, so he could get better medicine and recover soon. People told us that they did not go to the puskesmas unless they felt really sick. Yet, when they went there the health providers tended to underestimate their illness.

Some families said it was the doctors that were their reasons for not going to the puskesmas. They said that the doctors were rude and they underestimated "[us] the village people as if we are stupid." One mother said that once she asked a doctor to check her blood pressure. The doctor replied, "Oh, I will get so tired if I checked the blood pressure of all patients who come here."

Field notes, Sumba Peri Urban.

Across all locations, most people preferred private clinics or private hospitals to puskesmas. People said to us that they considered the service in private clinics and hospitals to be good, with an absence of long queues being particularly important. When seeking treatment at a private hospital, Papuan people in Timika City shared that they could meet the doctor and receive the medicine within the hour. "... more doctors, nurses, more room for in-patient care, and the service is quick," said them to us about the hospital. Families in Sumba Peri Urban were even willing to drive for one hour on a motorbike to the private clinic as the clinic provided what they considered to be good medicines. A father in Manokwari Urban told us that his go-to private clinic provided patented medicine which he believed to be better than the generic pills given out in puskesmas.

#### **MALARIA CADRES**

Malaria cadres were only available in three locations: Jayapura Forest, Jayapura Lake, and Timika City. People became cadres through volunteering or they were asked by the head of RT. Some of them had been cadres for other purposes before. The cadres were trained before they took on the role and some, such as in Jayapura Forest, went to some refresher training in the following years. People generally considered cadres as well-known people in the area and were able to communicate well with people. Only in Timika City we found cadres were once rejected and catcalled because people were upset about the malaria test that did not come out immediately. In places where there was no malaria cadre, such as in Sumba Peri Urban, the current cadres were usually asked to help with malaria services. They distributed bed nets and helped with mass blood testing held by puskesmas, although they usually only tested those living near their houses.

Malaria cadres were usually equipped with RDT tools as well as complete malaria pills including Dihydroartemisinin-Piperaquine (DHP, which people called the blue pills), primaquine



A malaria cadre testing for malaria.

(which referred to as the yellow pills or the brown pills) and paracetamol which they would restock at the puskesmas. Some cadres in Jayapura Forest however charged people for the malaria medicines although they were free. One mother who paid IDR 20,000 for the medicines said to us, "I know [the medicine] is supposed to be free—but this is not from the puskesmas. She [the cadre] said she buys this herself because she ran out".

Malaria cadres in Jayapura Lake however often ran out of medications particularly when malaria cases were high usually during the rainy season. The malaria stock lasted only for two weeks after which the cadres needed to restock. The malaria cadres first sent photos of their record books to the puskesmas as a proof of the need for restocking however they were told to bring the record in person. This was difficult to do due to the distance and the transportation needed to go to the puskesmas. In addition, the road was difficult for travel which caused puskesmas staff suspending their visits to the village. Yet, the cadres were still expected to travel to puskesmas for a restock.

When cadres arrived at the puskesmas, the staff in charge was not always present and the cadres could not obtain the medicines which was particularly problematic during malaria season. Because of this, sometimes people could not get enough malaria medicines for the whole treatment when they visited the cadres. The cadres would then suggest them to go themselves to the puskesmas which was 1 hour travel from the village.

In Jayapura Lake, malaria cadres were the first point of contact for any kind of illness, including malaria, as well as for birth delivery because there were no other health services available in the village. The cadres also ran a monthly health session in the village which combined posyandu sessions with a general health check-up for the community. All cadres tried to make sure that people take their pills as prescribed. Some would also check whether people used bed nets and took pictures of the nets being used. After bed net distribution, the cadres in Jayapura Lake would accompany puskesmas staff visiting people's houses to check on bed nets usage. Some people

there told us that when the staff came they would

"just tell [them] that we use it. Because they already gave us this so they will be sad if we don't use the net or don't like it."

The work as malaria cadre could be overwhelming for some. In Timika City, one malaria cadre was looking after a population of 5,000 people and they did not think their compensation was enough (IDR 500,000). Some people in Jayapura Forest also thought that cadres did not always follow their own advice. A cadre there was feeling unwell when we met her and she tested herself for malaria. The RDT showed a positive result but she did not take the medicines because the medicine gave her a stomach ache. When hearing this, a woman said, "she tells others to finish the medicines but did not take herself"

#### **HEALTH SEEKING BARRIERS**

# People told us that they mostly did not have any problems in accessing health services.

In most cases, puskesmas were available in the village and in some places, pharmacies, clinics and hospitals were also nearby. Most services were free or cost little, around IDR 5,000 without the national health insurance (BPJS) to get treatment or around IDR 10,000 for registration. Malaria medicines were free if tested positive although medicines bought in kiosks or pharmacies without prescriptions did mean people paying out of pocket.

However, some people still encountered barriers in accessing health services. Health providers in some communities were only available outside the villages, incurring travel cost when people need to visit. The cost varied depending on the mode of transportation used and the distance travelled. In Sumba Peri Urban, where the puskemas is 1 hour motorbike ride away from the village the travel cost IDR 15,000 for a one way trip with an ojek (motorbike taxi) or a shared car. It cost IDR 150,000 one way, if travelling with a privately rented car. In Jayapura Lake, people told us it cost them IDR 30,000 to rent their neighbour's motorbike to go to the puskesmas

located 45 minutes away or IDR 100,000 to rent a car. The distance and cost barriers were particularly challenging in Jayapura Lake where public transportation was rare that they would wait up to an hour for a car or truck passing in order to hitchhike.

Both in Jayapura Lake and Sumba Peri Urban, there were cars made available by the puskesmas or the village for people to travel to health providers. However, they were not always accessible for different reasons. In Jayapura Lake, the driver was not always available to pick up patients while in Sumba Peri Urban the car was used for other purposes that the village head stopped letting people use the car.

Limited operating hours of puskesmas was also a barrier that in some cases led to people missing out on health services. People in Jayapura Forest and Timika City shared that they waited in long queues at the puskesmas which made them reluctant to seek treatment there. In Jayapura Lake, people often had to wait hours on the side of the road to hitchhike to the puskesmas. They then had to stand in a queue, only to miss the laboratory service hours. Because of this, people told us it was 'good' if they tested positive for malaria which meant they could be treated by the village cadre rather than finding out that they might need to check for other illnesses and travel to the puskesmas.

# SOCIAL DYNAMICS AND HEALTH SERVICES DELIVERY

In some areas, there were evident tensions between health service providers and the patients.

This was reflected in service delivery as health service providers often treated patients differently. Health staff in the study locations tended to be stationed temporarily in the area. They are also more likely to mingle among themselves, not trying to get to know the community. Some mothers felt awkward when visiting puskesmas because the nurses ignored them while

continuing talking with other visitors whom they knew better instead. People also felt that the health staff were rude and dismissive, telling them to wait or go to a different table. One mother in Timika Island shared with us of her experience dealing with the health staff. "They were giggling and watching mobile phone in front of me," recalled her, telling her to "... sit here, go there, do you understand!... why should I have to do this?" People in Timika Island told us they preferred to have some health staff over others because the preferred ones "... know our name". This was confirmed by the health providers who told us that patients do tend to listen to some health staff than others.

Health providers, such as those in Timika Island and Timika City, were sometimes frustrated because they thought patients did not understand their instructions (Box story: "Being firm with people"). Health providers also considered the patients impatient when seeking health care and that they did not take care of themselves. When people in Timika City refused the IRS, health providers viewed them as being uncooperative. However, people shared with us that they did not want the spray because it was not natural and could bring new kinds of mosquitoes to the area. As for being considered as impatient, a man in Timika City shared with us that they complained of slow service because they saw the nurses were chatting with one another. Cadres, on the other hand, said they felt hopeless in convincing parents to take their children to the posyandu, saying that the mothers believed their children were healthy so there was no need to take the children to posyandu.

#### Being firm with people

When the MalCon team conducted IRS, they also did malaria screening for the community. "It's for everyone," said the staff to the people in Timika City although people told us that the screening car was stationed on a main road and only a few housewives and children voluntarily came to take the test. The nurse acknowledged that they missed many people especially those who were at work during the time of the screening. At one time, a mother approached the nurse and asked for a bed net because she had not received it. The nurse replied to her with questions, "How could you not get any? Where were you on distribution day?" The mother stayed silent. "Are you using bed net at home?" to which the mother muttered, "Hm, not really. There is no mosquito inside my house." The nurse looked visibly upset and started to scold the mother, "How could you know there is no mosquito? You are sleeping, right? How could you know?" The mother looked scared because she was scolded in front of the neighbours. She started shaking. Yet, the nurse continued yelling at her, "Why are you shaking? Are you ill? Talk to me!" The mother was then told to ask the nurse's assistance for the net. As the mother left, the nurse said to us, "I'm usually firmer to them - not soft like that. People here won't listen if I am soft." "I will go to her place, set the bed net, take a picture, let her sleep under the bed, take a picture," she continued, "... next time I visit, I will come again to her home, to see if the bed net still there, take a picture and ask her to sleep inside the net". The nurse said pictures were important for her to be used in the reporting to her supervisor, stating that people complied in using the bed nets.

Field notes, Timika City.



A Papuan mother in Timika Island stood around awkwardly as she was being ignored by the puskesmas staff.

#### 4. BEDNETS: USAGE AND PREFERENCE

Among all of the prevention practices that people shared with us, the one that was the most often used was bed nets. Across all study locations people widely used bed nets on a daily basis. However, bed nets tended to be used more regularly when people noticed that there were more mosquitoes around. In seasons where mosquitoes were more abundant, including during the fruit season, people used bed nets almost daily. People also made sure they used their bed nets after rainy days as there were usually more mosquitoes around the house. Conversely, some might not use bed nets at all if the number of mosquitoes were considered negligible. Those who lived in brick houses often told us that there were no mosquitoes inside their houses and might opt for sprays, coils, or electric fans to keep mosquitoes away. An old woman in Timika City who lived in a brick house said to us, "I still have 20 bed nets. [I don't use them] because [there are] no mosquitoes here."

People tended to use bed nets in the evening while sleeping but some also used them while watching TV, playing with their mobile phone or while taking a quick rest. During the day, bed nets tended to be hung to reduce the chemical smell. They might also be stored away. When used in the evenings, people preferred not to tuck the bed nets under their beds because they found it a hassle to get out of it when they needed to go to the toilet in the middle of the night. Some also found tucking in the bed nets made them feel confined as the space under a tucked bed net became too small.

When sleeping, children liked to have their arms and feet outside of the bed nets as a force of habit and it felt more spacious, and they also picked at the bed nets making holes as a means of play. In Jayapura Forest during the day, sleeping babies were usually put on the floor under an umbrella shaped net. The net cost IDR 35,000 but it easily tore as the net was soft and spokes got stuck. Mothers in Jayapura Forest told us they

needed new ones every 3 months. This net was typically a newborn baby gift from the neighbours and it was also available from the big kiosk in the village.



Bednets were typically not tucked for easy entry and exit.

#### Women, children, and toddlers used bed nets more often and consistently while teenagers and men tended to use less or not at all.

Teenagers told us that they often slept without bed nets because they frequently fell asleep before having had the time to set up the bed nets. Men tended to not use bed nets as they liked sleeping where there was breeze. This meant in front of the TV, at the verandah, or outside of the house completely. They told us that the breeze shooed mosquitoes away so there was no need for a bed net. People who liked to sleep next to a blazing fire also told us that they found little needs to use bed nets as the fire would shoo away mosquitoes. These were particularly true for the elderlies or those who lived in wooden traditional houses.

# Although they tended not to use bed nets at home, men would carry bed nets with them and use bed nets when they were staying in the forest, typically during fruit seasons.

Men in Jayapura Lake told us this was because in the middle of the forest there were a lot of mosquitoes and without bed nets, it was impossible for them to sleep due to the noise. One grandfather in Jayapura Lake shared with us that he did not allow his grandchildren to come with him to the forest during fruit season because there were a lot more mosquitoes than usual. He also made sure that he wore long sleeves and long pants, a prevention practice that was also commonly used in all study locations when going to the forest although some people in Sumba Peri Urban mentioned to us that they did not own long sleeved shirts so this was not a possibility for them.

#### Even though people were familiar with bed nets from using them fairly regularly, there was quite some confusion on how to take care and maintain bed nets despite the packaging of the bed nets having instructions on how to do so.

Some people shared with us that they washed their bed nets once a month while others, such as those in Timika Island, only did it once. People in Sumba Peri Urban washed their bed nets every three months. Often the frequency of washing depended on the information people were given by the people distributing or selling the bed nets to them. People also shared with us that some of the bed nets they were able to repair but some others they could not.

People shared with us that the main reason why they were using bed nets was to escape bothersome mosquitoes but not because the mosquitoes brought malaria. People said mosquitoes' noise prevented them from sleeping and when they did fall asleep, they could not "... slap the mosquitoes away," if any came to bother them. People also told us that bed nets protected them from the wind and kept them warm. Some people, typically the elderlies, used bed nets due to old habits. These were the people who had been using bed nets since they were younger and



Bed net packaging showing how to maintain and wash bed nets.

some were traumatized by bad experience with malaria in their younger life which motivated them to be diligent in using bed nets.

Those who did not use bed nets had numerous reasons and often it was because sleeping under a bed net was too hot for them or made them feel restricted or uncomfortable, especially when the bed net was too small for them or the house was too small for a bed net. Although some people found ways around feeling too warm sleeping under bet nets such as mothers in Jayapura Forest who decided to sleep bare-chested. "If [it's] too hot, we open our clothes but [we] always sleep under [bed nets]," explained them.

Some people disliked the chemical smell of the bed nets. Parents in Manokwari Urban considered bed nets with smells that were too strong to be toxic for children as the nets stung their skin and caused rashes (Box story: Allergy from bed nets). They told us they would rather use mosquito spray or electric fans rather than bed nets to keep mosquitoes away.

#### Irritation from bed nets

Most mothers we talked to acknowledge the benefits of using bed nets while sleeping. However, a mother (35 year-old) in Jayapura Lake said that she and her five children developed an allergy from using the new green bed net distributed by Puskesmas in October 2020. They often woke up in the morning with itchy rashes and bumpy skin on their arms and hands from touching the net. "If we touch the bed net, our skin will be itchy and bumpy," said her. This concerned the mother because all of her children were always shirtless and moved around while sleeping, increasing the risk of irritation. The mother said the green net had a very strong smell, making her think that the net contained more chemicals. It also creased easily and was more stiff than previous bed nets. Nevertheless, the family relied on bed nets to protect them from mosquitoes at night. She then decided to sew together two old white bed nets to make a bigger and safer bed net for all her children to sleep underneath. The mother and father still used the green bed net to sleep.

Field notes, Jayapura Lake.



Some babies in Jayapura Forest slept under 'umbrella' mosquito net during the day.

It was common for people to have extra bed nets than needed. Some stored away these extra bed nets and used them whenever they have guests staying over. Some gave the bed nets away to their relative who lived more remotely and did not have access to bed nets. Children also used the extra bed nets for playing and in Timika Island, people sold their unused bed nets to kiosks for IDR 150,000. The kiosks would then resell the bed nets for IDR 200,000. Old or broken bed nets were repurposed. In Jayapura Lake and Timika Island people used old bed nets to catch fish. Some people, such as those in Sumba Peri Urban and Jayapura Lake, used old bed nets in their gardens to protect plants from insects and pigs. In Manokwari Urban, people used their extra and leftover bed nets to make Christmas trees.

People mentioned to us that they usually received their bed nets from puskesmas and they had been receiving bed nets every year since the mid-2010s. People in Timika also received their bed nets as part of MalCon's programme. Most people last received their bed nets in October 2020 and the bed nets were distributed based on the number of rooms or sleeping arrangement in the house. The bed nets were either delivered directly to people's houses or they could be picked up from one collection point. When receiving the bed nets the people who distributed them did explain how to use the bed nets properly but people said that they were never told that the bed net usage was linked to malaria prevention. Sometimes, puskesmas would also check whether people had put up the bed net correctly (Box story: Bed net sweeping). A few people did share with us that they missed out on the last bed net distribution or only received one bed net when needing more which they usually attributed to them not properly registered by the head of RT. Some pregnant women received their bed nets from posyandu and they were often prioritized for leftovers.

#### Home checks on bed nets usage

Puskesmas staff in Manokwari Urban made occasionally home visits to check on bednet usage. One mother told us that one day she heard the spot check were being made, she immediately put on the bed net over her bed. When the Puskesmas staff arrived and checked her bedroom, they said that her house was the only one using the net—not knowing that the mother just installed it before they came. She was then rewarded with another bed net.

Field notes, Manokwari Urban





The left bed net was from the government and had big holes. People in Manokwari Rural liked the left one better which they bought themselves in the market. It was made of muslin, with smaller holes and looked pretty.





















#### Captions for photos

- Leftover bednets from the distribution used for Christmas tree
- (2) Bednet for catching birds
- (3) Net for fishing shrimp
- (4) Old bed nets used to protect garden from chickens
- (5) Net for fishing
- (6) Fencing the garden with bednets so dogs and pigs cannot come into the garden
- (7) Old bednets under the house, kids used them for play
- (8) Old bednet used to cover water tank
- (9) Bednets to catch fish
- (10) Net for Fish Cage
- (11) Ripped bed nets were used to catch fish or to protect garden



People shared with us that they had preferences when it came to bed nets. The new green bed net that was distributed in October 2020 was widely disliked. The bed net was rough and stiff, "... feels like a fishing net," said people to us, and it smelled strongly of chemicals. Some people noticed that the net even killed spiders and scorpions caught in it. The net stung when it touched the skin and children developed bumpy and itchy rashes. The net also had bigger holes compared to the older ones people had which allowed gnats to get in.

The old bed net was generally preferred. People referred to this bed net as 'the white one'. They told us that the white bed nets were softer and more comfortable, "... feels like a blanket". The bed net also smelled better. Some people preferred a bigger size net as they tended to sleep in a group of five to seven people and they could not do so with the current bed nets did not allow them to do so. People also told us that they liked bed nets that looked beautiful either

with some colors or certain patterns such as floral patterns. Because of these preferences, people in Manokwari Rural rather bought their bed nets from bed net sellers which cost them IDR 200,000 to 250,000. They told us this way they could pick the size that worked for them and could choose the ones that were softer and prettier.

#### **5. PREVENTION PRACTICES**

Although being aware of the presence of mosquitoes and often feeling bothered by them, people in the study locations did not often use any particular prevention against mosquitoes and would only do so when they considered there were more mosquitoes around than usual. When at home, people usually only used the bed nets as a prevention practice and some used fans to blow away mosquitoes. We observed that no one in the study locations put up mosquito nets on their windows. When going or being in areas where mosquitoes were more abundant, such as the

toilet, people told us that they would just slap the mosquito whenever they saw one. If they were going to places where mosquitoes where especially abundant, such as when working in the forest, the farm, in the bushes or when doing planting or harvesting, people shared with us that they did use some level of prevention, such as using repellant, wearing long sleeves or making smoke to shoo mosquitoes away. They also carried bed nets with them when staying in the forest for a period of time.

However, people said to us that when they did use protection against mosquitoes it was because they found mosquitoes to be especially annoying but not because they were trying to prevent malaria. They told us that the malaria pills were very effective to cure the symptoms so there were no reasons for them to bother with prevention. Migrants who travelled to their home in other places in Indonesia often brought malaria pills with them as a precaution if they contracted malaria before they travelled (Box story: Misdiagnosed).

#### Misdiagnosed

An elderly Papuan man in Manokwari Urban told us that years ago he went to Bogor, West Java, and had a fever. He believed that he got malaria because he had the typical malaria symptoms. He had brought some malaria medicines as a precaution but did not get better after taking them. As suggested by his friends, he then visited a hospital and was diagnosed with typhoid. He did not believe this and would not take their prescribed medicines and treatment. The man instead continued taking his malaria medicine and eventually got better. This experience assured him that hospitals outside of Papua were unable to diagnose and treat malaria. Since then, he always takes malaria medicines when traveling outside of Papua as a precaution.

Field notes, Manokwari Urban.

When people used prevention in the form of repellents or coils or spray, they bought them from the local kiosks. People who lived in places where the kiosks did not sell these items tended not to use any repellants or coils or spray in their everyday lives. The reverse was also true, i.e. where people did not use repellants or coils or spray in their everyday lives, their local kiosks tended to not sell these items.

Some people in Jayapura Forest and Manokwari Rural told us that they did use repellent lotion to protect from mosquitoes. Although most people across study locations found repellent to be expensive and it was not preferred over coils or spray because repellant was only able to be used to protect one person. Some families in Sumba Peri Urban and Jayapura Lake made their own local repellant from herbal plants they had around the house. Mothers in Jayapura Lake used red lemongrass, ginger, and coconut oil and rubbed them on their hands and feet.

Mosquito coils were used in Manokwari Rural and Jayapura Lake. People there found coils to be a preferable alternative than repellant as they were cheaper and it lasted all night. Although some shared with us that they did not like the smell coils made. "It makes you cough ... hard to breathe," said people in Jayapura Forest to us.

People in Jayapura Forest, Manokwari Rural and Timika City liked to use spray in the house to prevent mosquitoes. They said they particularly liked it if the spray smelled nice or flowery. Some people in Manokwari Rural used the spray for the outside of their bed nets to increase protection.

Apart from being used by those who were staying in the forest, creating smoke or burning wood was a practice that was usually done by people who lived in wooden houses to shoo away mosquitoes. People told us that this was an effective method because mosquitoes dislike smoke. This practice was done in Timika City and people burnt the wood at the back of the house to achieve the



IRS is still conducted by the Malaria Center in Timika but less regularly than before.

effect. One father in Timika City told us that he sometimes would also use spray but burning wood was his preferred method as woods were readily available in the area.

People in study locations mentioned to us that they lately did not receive any indoor residual spraying (IRS). People in Sumba Remote, Manokwari Rural and Manokwari Urban told us that they never received IRS. One head of a neighbourhood unit (RT) in Manokwari Urban informed us that the village needed to make a specific request to receive IRS for malaria. He contrasted this with dengue. He said if there were dengue cases detected in the area, the village would receive spraying almost immediately. People in Manokwari Urban did recall some spraying that happened in 2020 in the market area but they told us that the spraying was related to COVID not malaria.

Both Jayapura Forest and Jayapura Lake experienced some spraying with the last round for Jayapura Forest that people remembered was in 2019. While people in Sumba Peri Urban only remembered fogging that happened in 2020 which they thought was for malaria. However,

the puskesmas staff told us that the fogging was actually intended for dengue.

Only people in Timika Island and Timika City received IRS regularly. The programme is organized by the Malaria Center, a joint organisation established in 2013 consisting of the Malaria Control (MalCon) and LPMAK (an institution for Kamoro and Amungme, two native ethnicity groups in Papua), organized by Freeport, and Mimika's health department. MalCon was a form of Corporate Social Responsibility (CSR) programme on malaria founded by Freeport. In Timika Island, the spraying was done yearly, coinciding with MalCon distributing food parcels to the residents of the island. In Timika City, the spraying was done twice a year although local Papuans refused the IRS due to them considering the spraying to be chemical based and therefore "not natural".

# STUDY IMPLICATIONS

The following implications draw on the conversations that our researchers had with families, community members and health service providers. They are also based on observations and direct experience from the researchers across the study locations.

Many insights were gathered around supply-side constraints such as inadequately staffed malaria testing laboratories, malaria medicine supply out of synch with seasonal demands, limited opening times of government health facilities and inconsistent inadequate appointment of puskesmas staff and cadre as malaria specialists. However, the implications that follow concentrate on the insights which need to be considered when designing the communications strategy. We have used the COM-B framework to frame the implications.

#### PEOPLE'S MOTIVATION TO ACT

Since the introduction of effective malaria treatments, people no longer consider malaria to be a serious or fatal disease. Furthermore, the incidence of acquired immunity, especially among men who have been infected multiple times, has led people to downplay its seriousness. On the whole, people indicate that malaria is endemic and they have learned to live with it and have no expectation that it can or will be eliminated.

The disease is viewed entirely from the individual's perspective and little is understood about transmission and the perpetuation of the disease in the community when individual's symptoms are not considered severe enough to seek testing and treatment or treatments taken are incomplete.

The combination of acceptance of malaria as 'here to stay', effective treatments, acquired immunity and lack of knowledge about transmission results in minimal motivation to change behaviours and therefore presents a challenge for SBC interventions.

The widespread and regular distribution of bednets has been welcomed as were IRS programmes which have now stopped or are rare. However, the main motivation for this appreciation is the mosquito annoyance factor rather than protection against malaria. Disturbance to sleep and the irritation from bites are the main drivers for mosquito control and explain why men, in particular, only take preventative measures if they stay overnight in the forest. Communication, if done at all at the time of net distribution (and it most often is not done) concentrates on airing new nets before use, washing and care of the nets rather than reinforcing why using bednets is the responsible thing to do to limit transmission.

#### PEOPLE'S CAPABILITY TO ACT

The study has found that very few communication programmes designed to raise awareness of malaria prevention and treatment are currently active, not even during the high prevalence season with which this study coincided. Children had mostly not been taught about malaria at school. Knowledge was mostly acquired through direct experience with the disease when relatives and those residing in the area for long times were the first sources of information and advice. At points of service for testing and treatment, people are given instructions and have acquired knowledge of different types of malaria and different treatment regimes. However, the exhortations to come for early testing and completing medication have not been internalised. These behaviour changes require people to understand why these measures are

important not just for their own health but to break transmission cycles.

The study also indicates that, unlike other parts of Indonesia, social media and TV are not much used, and when they are it is purely for recreation and not a source of information. Furthermore, the few graphic materials such as posters, banners and leaflets that were present in communities were not noticed or remembered by people. When specifically discussed with people, they were found to resonate little as they did not depict real situations or real livelihoods which people felt able to relate to. If such materials are to be used, and their value is arguable, then people shared that they would like to have photographs depicting relatable situations and very few words.

More preferable across all study locations is interpersonal communication (IPC). People distinguish this from the instructions they get from health service providers noting that effective IPC is an informal opportunity to have two way conversation in a comfortable space with time to ask questions and ensure understanding. This explains people's shared preference for seeking advice from local nurses and cadres, often in their own home rather than feeling uncomfortable in situations where they are only instructed what to do, feel talked down to and sometimes shamed and blamed.

The study in Sumba gathered insights into how the private foundation clinic in Sumba Remote has improved IPC when people come for testing and treatment. Our observations found that each patient was given time for full explanations to be given and questions answered. The behaviour of staff was regarded by patients as friendly and non-judgmental. Uptake of the suggestion to return for re-tests after medication (without extrinsic incentives) was high whereas in other study locations this rarely happens. Comparison with the interactions observed elsewhere suggest that improved IPC skill of health service providers would contribute to positive behaviour change.

The lack of education around malaria in schools in endemic areas currently suggests that there is a significant gap. Basic understanding of transmission and concomitant need for early detection and completion of medication would not only help support capability to change student behaviour but could be linked to student-led mosquito control efforts at their schools (often observed to be some of the worst affected places in communities). Knowledgeable youth may also be important sources of information for family and neighbours.

The study indicates that women invariably have more knowledge of malaria, testing and treatment than men, who often fail to take malaria seriously or procrastinate or avoid taking action. In order to motivate the whole community to recognise how they can contribute to the elimination of malaria, it would seem imperative to target men and boys in particular.

New migrants to the area (and those returning after considerable time away) are especially vulnerable to serious effects of malaria and the study shows that they rely on local neighbours for advice. Information about the disease and the nearest testing services could be more readily available on arrival, for example at local administrative unit offices when they first register residency.

The predominant view of mosquitoes as a nuisance rather than as a transmitters of malaria is one reason why little action is taken to control mosquito breeding sites. Combined with the decreasing willingness to engage in voluntary community work without tangible (preferably cash) incentives (especially in Papua) has resulted in limited community action to address environmental factors which increase risk. Education around environmental control, including better drainage and waste disposal as well as cultivation of mosquito repellent vegetation, is lacking and few efforts are made to invest village funds on mosquito control. Building better co-operation between the puskesmas and the community could lead to better sharing of information about transmission and risk which in turn may focus more effort into local mosquito control.

#### PEOPLE'S OPPORTUNITY TO ACT

On the whole people do have relatively good access to testing and treatment facilities. In urban areas there is a wide choice of services and convenient opening hours. In some rural areas people depend on cadres (as puskesmas is far) and the study indicates they offer personal and effective testing and treatment. As noted above there are supply-side inefficiencies and weak planning and coordination to respond to malaria peak seasons but more problematic is people delaying seeking tests and non compliance with treatment regimes.

This study reveals the importance of trust when people avail health services. Generally, among those who had a choice, private services were more trusted than government. Irregularities in supplies of testing and treatment resources, peremptory interactions between providers and patients, unresponsive after hours service, low confidence in the skills of technicians (e.g. false negative results often cited) and the general view that government services are often minimal (e.g. provision of generic medicines for a range of ailments) means that trust is often low between government health service providers and communities. Increasing accountability to communities and improving service culture would be expected to contribute to building cooperation and coalitions to eliminate malaria.

Given that people appreciate and trust malaria cadres and the enhanced 'opportunity' neighbourhood based services provides for early testing, personalised counselling and home follow ups, increasing the numbers of cadre specially designated as malaria cadres may contribute well to behaviour change. It also recognises the study finding that these cadre often feel overwhelmed with too many calls on their time and services. Given the need to boost the motivation and capability of community men in particular in relation to combating malaria, more male cadres may be advisable.

Although access to RDT is quite good, people are concerned about its reliability. Where laboratories

for microscopic tests are far away or not properly equipped there may be case for mobile testing units such as observed in Timika city operated by MalCon.

Good quality and up to date advice was not always available in health facilities. Especially concerning was the finding that pregnant women were being advised not to take malaria medication by health service providers based on outdated guidance. In order to ensure there is opportunity to change behaviour, health staff must be familiar with the latest Government protocols suggesting a need for refresher training.

Whilst bednet distribution has been efficient and all households in the study had bednets, the poor quality of the most recently distributed nets may affect future usage. The latest government issued nets are described as rough, stiff, smell strongly, irritate the skin and have bigger holes and are more difficult to tuck in as they are smaller than previously supplied nets. There was particular concern expressed about using these for young children. Such concerns may adversely affect usage with either no nets being used or old nets resorted to (with any insecticide impregnation washed out), especially as people's main concern is to prevent the irritation and buzzing of mosquitoes rather than malaria prevention. User feedback should be taken in consideration when designing bednets to enhance their useability.

#### **NEED FOR MORE BEHAVIOUR-BASED STUDIES**

The study has revealed a disconnect between what people do and what they say they do. When asking them to describe steps in seeking treatment they often indicate that they do test early and do take all the medicines. However, deeper discussion and observation provide insights that this is not the case (e.g. many households had unused medication in their homes). Similarly spot checks on bednet use which are often undertaken by cadre and puskesmas staff fail to recognise that people are using them to stop mosquitoes irritating them rather than linking this behaviour to malaria control. This suggests a need for more qualitative studies, especially those including immersion or participant observation, to understand these behaviours which quantitative survey based research is unlikely to expose.



# ANNEX 1. STUDY METHODOLOGY

The research focused on deep situational assessment in particular to understand the barriers and enablers of target groups to access malaria services, and factors affecting this in order to find the best ways of reaching the target groups and motivating behaviour change. Such research is essential to the design of effective communication tools and approaches which are culturally and geographically appropriate. The approach we used for this formative research was strongly participatory and collaborative and put the 'target group' at the centre of identifying barriers, the need for change and codesigning the means for change. Informed and preceded by a desk review, the assignment was implemented in four phases, each with a strong focus on humancentered design and innovative methods.

#### **DESK REVIEW**

The desk review was undertaken at the start of the assignment as the first deliverable. It informed this study design and comprised relevant studies and program documents about malaria intervention in Indonesia with emphasis on social determinants and community behaviour.

Sources included publications from Indonesian Ministry of Health, WHO, Global Fund, and academic journals. Empatika also consulted the malaria expert for this study, Enny Kenangalem, a medical doctor based in Mimika who specialises in malaria control, for her insights and inputs to the review. A stand alone document was submitted to UNICEF on 30 December 2020.

# Participatory community assessment and participatory barrier analysis

The participatory community assessment and participatory barrier analysis were done throughout five days of the adapted immersion period. The initial study design was to implement participatory community assessment for two days, one day break for the team to discuss topics

that would be examined further in the last two days of participatory barrier analysis. The research team was able to conduct both throughout the five days without the break.

The participatory community assessment was done through an adapted immersion that drew on Reality Check Approach (RCA). An adapted immersion involved visits in the day and early evening only, rather than full immersion which involves overnight stays. This modification was done to mitigate the infection risk posed by COVID-19 to researchers and participants. Full RCA immersion typically involves trained researchers living with people in their own homes and sharing in their everyday lives. In this adapted immersion, researchers spent time with families, jointly undertaking chores and normal daily activities including recreation and meals, to ensure an informal environment of shared experience.

The participatory community assessment looked into understanding the community context particularly related to (a) access to malaria services and (b) community members' behaviours towards malaria intervention. Malaria service delivery in the area was examined from both community and service providers' perspectives. Informal conversation, one of the tools used in adapted immersion, enabled researchers to gain insights into people's experiences with and their views on malaria services. Through informal conversations, researchers were also able to learn the appropriateness of messages of malaria service providers and how they were received by community members. First hand observation allowed researchers to see available service delivery in the area as well as community's access to them. Researchers also engaged with other service providers such as the local government and teachers to obtain further insights about service delivery.

In looking at the community behaviours, the adapted immersion focused on identifying behaviours that might support or hinder malaria prevention: what people did, how and why they

did so. The adapted immersion also allowed researchers to dig into people's knowledge, beliefs or norms that determined their behaviour towards malaria intervention. In addition, the community assessment identified preferred and trusted information sources as well as communication channels used by community members, and their potential usage in supporting malaria control programs.

The participatory barrier analysis drew on the Barrier Analysis approach which was a rapid assessment tool to identify enablers and barriers to adopting a particular behaviour. To identify these enablers and barriers, a questionnaire was used to ask the target group about determinants that blocked a certain behavior (barriers) and what they thought were positive consequences (promoters) of the same behavior. The analysis then compared the responses between the group who did the behaviour (the Doers) with those who did not (the Non-Doers), to identify the most important determinants which would be highlighted in health promotion and program design.

For this study, the barrier analysis was implemented through a participatory qualitative-based approach using adapted immersion.

Participatory barrier analysis done through adapted immersion allowed for informal conversations to be used as one the main data gathering tools.

Informal conversations created open, relaxed spaces for researchers to explore with families and community members enablers and barriers to positive behaviour in malaria intervention, and therefore obtained their genuine insights.

This also gave the researchers opportunities to include localized practice that might not be captured through administering a predetermined questionnaire.

We also approached community members without predefined questions or expected answers. This facilitated easy interaction with communities by reducing bias from study participants who might respond with what they believe to be socially desirable, especially when it related to behaviour. The adapted immersion also

ensured we engaged with all voices (the Doers and Non-Doers) and talked about behaviours that hindered or supported malaria intervention. Importantly, as this was done in a relaxed and informal manner free of a check-list or a questionnaire, interactions took a non-evaluative tone, allowing both Doers and Non-Doers to share openly and candidly without feeling one was more 'right' than the other.

#### **AREAS OF CONVERSATION**

Researchers' exploration of these issues with people on the ground was guided by an Areas of Conversation (AoC). An AoC is a list of relevant topics to be explored in situ during the adapted immersion. An AoC is adaptive in nature and it provides researchers flexibility when engaging with study participants. Instead of having to follow prescribed questions, the researchers can engage in natural conversations with people on the ground while having the AoC as a point of reference of topics to explore informally and organically during that informal and relaxed exchanges.

The AoC served both participatory community assessment and barrier analysis. For participatory community assessment, research team specifically focused on exploring people's behavior, knowledge, and experience related to malaria to have an understanding of the picture at the community level, and for participatory barrier analysis, the focuses were on the individual level responses and prevention of malaria, particularly on the category of people who were the doers and the non-doers.

The AoC was developed from the Desk Review gap analysis which was augmented by the Malaria Matchbox Tool, <sup>11</sup> an assessment tool that was designed to improve malaria responses by looking into how social, economic, cultural, and behavioral factors present barriers and opportunities to malaria service delivery.

<sup>&</sup>lt;sup>11</sup> Malaria Matchbox Tool. The RBM Partnership to End Malaria and The Global Fund. https://endmalaria.org/ sites/default/files/Malaria%20Matchbox%20Tool\_en\_ web.pdf

#### Context

Community location, size, infrastructures house: location, type facillities/assets profile of the family age; education; gender; culture; religion; dependents; work (formal/informal), other income sources, origins; perceptions on family's socioeconomic status and proverty, health and malaria, infrastructures/facilities (clinic, hospital, pharmacy, ect.): opening, service, personnel facilities

#### Health seeking behavior

Types of health providers (formal, informal, traditional); (changes) views of these changes/health providers (preferences). Views of allopathic medicine. Reasons for consulting different HSP; triggers for seeking services; perceptions/expectations of quality in service provision: (quality, discrimination, comfort, trust, etc.) Barriers to seeking services (e.g. costs (incl. medicine, transport, opportunity costs, speed money etc) - access to financial help to meet these costs, consequences of borrowing, debt etc), physical access (distance, ease/effort, opening times, transport availability, safety);

Financial constraint/support/subsidy affecting prevention and treatment, indirect cost (loss of income, care responsibility, etc.) Malaria funding from village, community empowerment

HSP

attitudes/behaviour/language/social cultural issues).

Access and availability to relevant items (bednets (how old), malaria pills, mosquito repellant, spray, antenatal care, IPTp, IPTI, SMC,others?)
Household decision making related to health seeking, ANC

attendance/value/accessibility. Malaria information/commodities provided.

cadre-frequency/usefulness. behaviour.

#### **Behavior & Social Norms**

Behaviour changes: what help, messaging that works and wont, what or who convince them to change; What people considered positive/negative in the context of malaria (social norms, expectations); Social norms affecting behavior, relevant inequalities in a household (age, gender, etc.). Stigma related to malaria. Current trend (where hanging out, etc. what make people more

# Combined areas of conversation (informed by Desk Review, Matchbox Tool and Barrier analysis)

#### Perception of risk

Perceptions of malaria risk/malaria consequences to self, family, community, those most/least adversely affected & perceived reasons for this (men/women, young/old, pregnant, babies, those with HIV AIDs, others, incomers/indigenous; those with particular lifestyles/livelihoods, vulnerable groups); perceptions of immunity.

Expectation of healing or recovery, experience of illness, relapse, loss. Perception of illness, health, death. Stigma. Seasons/time of day; place (accommsdation/work/topography/ecology); clothes worn (colour, texture, cover); sleeping arrangements, house design.

#### Segmentation

Across all AoC, are there differences by gender, ethnicity, age (teen), income level, education, occupation, local/migrant, pregnant (how far along)? Differences between 'doers' & 'non-doers'? Any positive deviance?

### Diagnostic and treatment practices

Physical accessibility (distance, opening times, waiting times).

Resources available- staff, diagnostic equipment and reagents; treatments (adequacy of stock, expiry dates etc). Psycho-social accessibility - staff friendliness, relationships, trust.

Discrimination. Quality/clarity of information/instructions provided.

Medication (preventative/curative) compliance.

Adequacy of referral & follow up.
Local practices/treatment.

information/instructions provided.
Medication (preventative/curative)
compliance.
Adequacy of referral & follow up.
Local practices/treatment.
Malaria non-treatment - who, what
they do instead (esp.
children above 5 and men)
Expectations/experience for malaria
treatment- views, timing. efficacy,
adequacy & availability of testing
&treatment; side effects,
modification, health insurancecoverage/uptake, perceptions (of
worth), effect on further health
seeking

Consequences of contracting malaria.

#### Understanding/knowledge of disease

General understanding of disease (causes (medical/spirits & supernatural /winds etc), perceptions of seriousness (norms-fever, convulsions) types of treatment (allopathic, herbal, spiritual etc).

Knowledge of malaria (local names, how transmitted, local beliefs, local wisdom), distinction between malaria and other diseases (diarrhoea, fevers, COVID etc).

Why here and not other places.

Knowledge of cause of malaria/symptoms, knowledge of

malaria/symptoms, knowledge of consequences of getting malaria (anemia, low birth weight etc); mosquito related when, where, breeding sites, etc.

#### Information sources

Types of information source/channels (interpersonal, school, religious institution, health services, cadres, Village Government, adat organisation, TV, radio, social media, work place) -frequency of interaction, preferences, trust & reliability. Types of information -information materials available, prevalence/accessibility of relevant information information type preferences, picture and word literacy, relatability, usefulness. Effectiveness of malaria messaging. Cultural appropriateness. Language used/cognition. Village regulation on malaria.

#### **Preventation practices**

Local practices- timing activities, use of deterrents/repellents; talisman, rituals etc. house design. Knowledge, ownership and use of bednets (why take if not using). Factors hindering use (discomfort, impractical, distrust, beliefs, other uses, maintenance, no perceived link, expense, frequency/sufficiency of distribution etc). Care of bednets, effectiveness of use of bednets. Preference.

Workplace provisions/prevention measures. IRS activities - frequency; perceptions of pros/cons; concerns; IT uptake-knowledge of this/recipients, views, access, compliance.

Local management e.g breeding sites. Activities which increase/decrease mosquito prevalence e.g. irrigation, drainage, water storage, burning crops, stagnant water/grey water

disposal.

#### **OBSERVATION CHECKLIST**

To accompany barrier analysis that was done by having informal exchanges with community members, Empatika researchers also conducted direct observation of the environment, the surrounding, and the behaviors in the study location. The observation was guided by the list below.

#### Home (general inside):

Prevalence of mosquitoes in the house during day, dusk and dawn.

How are walls, roof constructed? Windows/doors fitted? Holes, state of repair? Are there nets on windows?

Are doors/windows kept open or closed at certain times of day?

Lighting- what lights are on, where and are they attracting insects? What time are they switched off?

Water for bathing? Is it stored, if so how? is it covered? Toilet water – covered? Lying water in the bathing area?

Reaction to geckos, lizards?

Sleeping arrangements- inside, outside, verandahs. Sleeping routines. Sleep wear.

#### Around the house:

Plants in pots/old tyres etc – are they standing in water? Evidence of mosquito larva? Any other containers with standing water? (toys, agricultural equipment, buckets etc)

Any leaking taps?

Waste water disposal? Where does grey water run off from the home? What is drainage like around the home?

Fish ponds nearby? Rivers/streams? Public water points? (standing water- prevalence of larvae)

Maintenance of bush /grass around the house.

## Accompanying to workplaces/livelihood activities

Timing of journeys to field, water bodies, forest for livelihood. Mosquito prevalence en route/ at work site. Prevention measures taken – clothing, repellent, routes taken, timing, overnight stays.

Livelihood activities overnight, dusk/dawn

#### **Prevention measures**

Bednets – describe whole process of erecting the bednets in the home (timing, sealing etc) and how people get under them, who uses and who does not.

Nets used at windows, doors etc- state of repair, opening/closing.

Any evidence of use of insecticides, repellents (commercial or local), coils or other means to repel mosquitoes. Use of these.

Any evidence of intermittent preventive treatment (IPT) for pregnant mothers? (packages, leftover tablets)

Review of baby books (Pink Book) which record doses of IPTi (intermittent preventive treatment for infants).

Observation of monthly posyandu- malaria advice, distribution of IPTs, distribution of bednets and advice provided, SBCC materials in the posyandu/ used by cadres and bidans, ways in which the ICT materials used.

Observation of work places, especially what preventative provisions provided.

Observation of recreation places. Who use them, timing, exposure to mosquitoes.

#### **VISUAL APPROACHES**

Conversations in adapted immersion were supported by the use of photos and visuals. These helped by:

changing the dynamic – moving away from talk to doing something engaging and perhaps having fun.

reducing inhibitions and letting people relax
—facilitating more open and non-judgmental
exchanges. In this study, it is important for
people to be candid in their behaviors in relation
to malaria prevention and action and the use of
visuals helps this to happen.

allowing people to talk about 'third parties' --rather than themselves directly, representing one kind of projective technique. This is especially effective for some sensitive topics. In this study for example, where people might feel embarrassed

that they are not taking sufficient precautions or are awkward about their reliance on old or local remedies.

Where appropriate, visuals were used to aid conversations. Visuals helped researchers engage in deeper conversations with study participants and experience showed that concentrating on a visual often made it easier for people to open up and explain issues. Below is a list of visuals that were used for this study:

**Socio-ecological mapping** was facilitated among several people from a community who together can build up a map of the neighbourhood. These maps depict houses, land use, water bodies, key facilities such as water points, health posts. People also identified sources related to malaria such as places with more mosquitos, toilets, locations where communities take mosquito control measures.

**Seasonality.** The common wisdom is that places like Papua do not experience a seasonal variation in malaria incidence as the climate is rainy throughout the year. However, this may differ from people's understanding of risk of infection. Charts are made showing the seasons in a way most relatable for people themselves (calendar months, agricultural calendar, severity of rains, festive seasons etc). Participants superimpose on these periods when they are most busy, have least income, get ill more frequently (by type of illness e.g. fever, diarrhea, coughs), can travel/ not travel, mosquitoes bother them most etc. Searching for correlations across these different experiences provide the basis for discussion with participants on their perceptions of risk and access to services.

**Daily activity charts.** Individuals are encouraged to think about all the typical activities they undertake throughout the day and night and place them on a 24 hour time line or clock. They are then encouraged to think about deviations from this at certain times of the year or when they have babies to look after, special events and celebrations. The times in the day when

mosquitoes bite most or are most irritating are noted. These are shared with others in the group and discussion can develop around activities which might put people more at risk to mosquito bites e.g. bathing/using toilet before dusk, feeding babies in the night, being outside the home in the evenings, recreation activities at night, washing clothes in stagnant streams etc.



Body mapping of where mosquito bit, done by children in Sumba Remote.

**Body Mapping** involves a group or individuals making a drawing of their body and identifying different areas on the body where they experience pain, chills, fever etc and describe symptoms of different ailments. This leads to further discussion on what they do about different conditions, when they seek treatment and the nature of that treatment. It may also reveal vulnerabilities in a non-threatening way as people may reveal underlying health issues which make them more vulnerable to the effects of malaria.

#### PEOPLE DRIVEN DESIGN (PDD)

PDD built on insights collected through the adapted immersion from which local and emic solutions to accessing malaria services and positive behaviour change could be generated from community members and local service providers. PDD was done in four research locations. In these four-day workshops, groups of community members were facilitated to work

together to co-create solution 'concepts' for behaviour change around the issues of accessing malaria services and positive behaviour change.

The workshops took participants through the findings from the adapted immersion phase and led an 'inspiration process' where a deeper understanding of needs and priorities were surfaced and shared. The 'ideation' process that followed encourages the generation of masses of ideas to solve the behaviour change challenges and to inform effective messaging on malaria prevention. Participants themselves were the ones who selected the most promising ideas, made the selected ideas contextually appropriate as well as created actual effect when realised through greater ownership and trust from expected future users themselves. The process concluded with the 'trialling' process where PDD participants tested the feasibility of their solutions and gathered feedback from other members of their community. These workshops resulted in participants coming up with ideas for visuals, messages, processes (e.g. service delivery improvement), activities. through highly creative brainstorming. The participants defined their own criteria for assessing the effectiveness of their solutions and used these as a basis to iterate and improve on their ideas, which were remotely supported by Empatika facilitators through phone and social media after the design workshops. Each of the four groups undertook a final review of their trials with the remote support of Empatika.

#### **Post Fieldwork Process**

#### **Debriefing**

Following the adapted immersion in each district, full-day facilitated debriefings were held with each subteam to download, reflect on and triangulate all information gathered during the immersion. Each researcher spent a full day sharing their conversations, experiences and insights with the overall team leader immediately after completion of the field immersion. These sessions explored the areas for conversations (AoC) and recalled conversations, experiences and observations

which were recorded in detail in written and coded notes. Detailed notes documenting this debriefing, along with photographs, annotated visual exercises, socio-economic templates for households and communities, written short case stories and field diaries from the immersion formed the 'data set' or basis of information from which study findings were drawn and research analysis was done.

#### Iterative analysis

Data was analysed following a 'grounded theory' approach, providing the basis from which the study analytical framework will be developed. The established approach of Framework Analysis was used to examine the large quantity of observational and conversational data from data collection includes:

- i. Familiarisation (immersion in the findings)
- ii. Identification of thematic framework (from the de-brief notes and the sense making workshop)
- iii. Charting (finding emerging connections)
- **iv. Interpretation** (drawing inferences from the charted summaries)

Empatika undertook this framework analysis process as a team consisting of a study leader, technical advisor, and study co-lead. These three people initially worked independently to test if the same themes would emerge. This is a key part of the analysis to add credibility and rigour (i.e. different researchers come to the same conclusions from the same written material). The key emerging narratives from this process were used as the basis for report writing. Quality assurance was carried out through internal peer review with special concern to ensure that the research retained positionality of people themselves.

#### Sensemaking workshop

Analysis was also done through a one-day sensemaking workshop. The study team leader led this workshop where results were further triangulated by the research team members from all locations to ensure that the emerging findings are consistent with the reality that the team observed and experienced in the field and rigorous enough to represent the views and perspectives of the people.

#### **PDD** analysis

After PDD workshops conducted, the workshop facilitators filled in archiving templates as a means to record activities conducted during the workshop as well as the result of the activities. The templates and actual visualised exercises were used as the basis for the team debriefing in which all facilitators come together to discuss the process and the outcomes of the PDD workshops as well as the preliminary trials. The team undertook review of the process of people-led design of solutions based on their own observations of the process and reflections shared by the participants themselves, augmented by follow up phone calls to review trialling after the facilitators have left the communities. Promising ideas for replication would be described in detail.

#### **Locations and Study Participants**

#### **Scope and Locations**

As agreed in consultation with UNICEF, this study was implemented in four districts: **South West Sumba, NTT; Manokwari, West Papua; and Mimika and Jayapura, Papua.** There were two study locations in each district which were selected in conjunction with UNICEF and local stakeholders.

Overall, the selected locations provide the most diverse profile, taking into consideration some criteria: malaria prevalence, relative accessibility to health services, geographical landscape (urban, peri-urban and rural, coastal, riverbed, in-land and city areas), as well as demographic profile (occupations, ethnic groups). Please see Context section for details of each location.

For the adapted immersion, four teams of three researchers went to each district for data collection (a total of 12 researchers). On the second stage for the human-centered design process, Empatika, in consultation with UNICEF, selected one location from each district to continue with the human-centered design process.

#### **Study Participants**

The primary participants in this study were families and community members living in high malaria endemic areas. This included vulnerable populations who have little immunity to malaria, such as babies and young children. The following criteria were used to ensure inclusion and diversity of experience and circumstances of people at higher risk<sup>12</sup> from malaria.

#### **Pregnant women**

Infants and children under five years old.

Migrants or mobile populations (for example those who commute regularly for work or work at risky roles such as in forestry and fishery).

The research team also interacted and engaged with formal and informal health service providers, local government officials, the elderly, key influencers (e.g. faith leaders, teachers) and other members of the community.

Child Protection and Research Ethics

#### **Child Protection**

Empatika as a research institution specializes in people-centered approach which is based on respect for people. It specifically supports the inclusion of multiple voices including children's. As such it takes very seriously the issue of child protection, not just in terms of risk management but also in terms of empowering children. The engagement with children is at all times respectful and best interests of the child is our primary consideration. In every step before and after the research process, child safeguarding has to be ensured. This includes time prior, during and after field research.

https://www.who.int/malaria/areas/high\_risk\_groups/en/

#### Research process before and after field work

Recruitment and contracting  - Reference check  - Local police check  - Sign child protection policy	Researcher training  - Full day session on child protection  - Refresher training pre-field departure		Study design & briefing  Optimise participation & inclusion  - Develop specific tools  - Protocol on child protection & consent
Risk assesment & mitigation matrix		Post field work	
- Identify possible risk		- Recording all issues encountered	
<ul><li>Identfy mitigation stategies</li><li>Assign focal person</li></ul>		- Discussion on action - Lesson learned feedback	
- Identify local referral		- Confidentiality & data protection	

**Before field work,** Empatika makes sure to follow a proper selection process of researchers as shown in figure above. Furthermore, since 2018 all Empatika researchers globally have to complete a comprehensive **full day training course** on Child Protection in Field Research. This training is based on Empatika's Child Protection Policy Guidelines and is consistent with UNICEF's ethical standards for conducting research with children. These standards emphasize:

- Informed consent and the right to withdraw
- Ensuring local acceptability
- Have protocol in place to safeguard incompetent researchers
- Ensuring a referral system is in place
- Doing no harm to children, family and community

Refresher trainings are also conducted prior to every study where all researchers are given the space to reflect on potential child protection issues related to the study theme. The protocol on Child Protocol Guidance and Checklist and Risk Matrix are filled out collaboratively in this session to give researchers deeper understanding of the child protection issues.

During field work, immersion studies are conducted using sub-teams whereby a small group of researchers (usually 3-4 researchers) go to one location and live relatively close to one another (typically 15 minutes away). In addition to this adding rigour to the data collection process, this also provides additional layers of support for dealing with ethical issues. Sub-Team Leaders keep in regular contact with team members when in the field and if there are any incidents then team members report this to their Sub-Team Leader. Community members are also informed that the researchers are working in small a sub-team and that other researchers are staying nearby. The immersion adopts a nonintervention based approach, which we believe further protects participants against harm. The only time researchers would intervene is if a child is in danger, in which case researchers are advised to alert parents or appropriate community support discretely and anonymously, recognizing the best interest of the child as suggested in the Child Protection Policy Guidelines. All researchers are trained to be alert to community dynamics and if anything arises to act in a sensitive and respectful manner, and if needed to move from households or locations.

After the field work each sub-team is debriefed by the study team leader. During this process the findings are shared, reviewed and cross-verified, and any ethical issues are raised including child protection. Following the debriefing, a 360 degree performance review process is also conducted with the Sub-Team Leader conducting this for each of his team members, as well as the team members conducting this on the Sub-Team

Leaders' performance. This performance review includes reflecting on the researchers' attitudes and behavior, the interactions with community members and their team attitudes and any child protection issue.

There are also multiple opportunities and avenues for team members and the overall team to identify and flag ethical issues. First, individual researchers have the right to protect any participants against perceived ethical misconduct by either not sharing information they believe in any way might harm or compromise a participant or by flagging any information shared during a debrief as something which requires further ethical consideration. Other sub-team members are also encouraged to flag any potential ethical issues during the debriefing process. Finally, the study leader(s) and quality assurance leader act as a final check against any potential ethical issues created by the research and against the dissemination of any information which might harm or compromise a study participant.

#### **Ethical Approaches**

In order to ensure that all studies are conducted in a high-quality ethical manner, Empatika conducts various procedures that are consistent and in adherence to UNICEF's three guiding principles of ethical evidence generation:

- Respect (treating all individuals, including children as autonomous agents),
- 2. Beneficence and Non-maleficence (research that promotes the well-being and doing no harm to individuals and community as a whole),
- **3. Justice** (considerations taken to avoid injustice and biases).

Adapted immersion methods also comply with the commitments of the International Charter for Ethical Research Involving Children, where (i) everyone participating in immersion takes responsibility to ensure the compliance towards the conduct of ethical research, (ii) respectful, just and equitable towards children, (iii) research does no harm and benefits children and (iv) obtain

children's informed and ongoing consent. Below are several approaches that immersion takes in applying these principles.

As per American Anthropological Association (AAA) Code of Ethics, Empatika adopts an ethical obligation to people when undertaking immersion and other qualitative research '[which (when necessary)] supersedes the goal of seeking new knowledge' (1996: p. 2). Researchers 'do everything in their power to ensure that research does not harm the safety, dignity or privacy of the people with whom they conduct the research' (1996: p.2).

Informed verbal consent from children and adolescents is obtained in accordance with UK NSPCC's guidelines, summarised as follows: consent from young people aged 16 and over might be obtained directly while consent from those who are younger will be obtained through their parents, guardians, carers, or other appropriate adults. Consent from young people aged 12 to 15 might also be obtained directly in contexts where they are accessing services under research independently. At the end of the immersion the research team will check with all study participants if there are any stories that they do not want shared, respecting their right to withdraw. Informed verbal consent is recorded by the researcher on a signed and dated form after the fieldwork.

Participants are also asked to provide verbal consent to being photographed and for the photos to be recorded and shared. Researchers take care that photos are taken in a way that is respectful of family and children's human dignity, rights, and wellbeing. Where children are photographed, the previously mentioned process of obtaining informed consent from young people applies and Empatika's Child Protection Policy Guidelines are observed. Taking photographs that respect study participants is an integral part of Empatika training and the study briefing.

As per the International Visual Sociology
Association (IVSA) Code of Research Ethics
and Guidelines, the use of photographs in any
publication ensures **confidentiality**. In the case of
children being depicted in photos, extra measures
are taken to obscure the identity of the child and
photo only depict children in a dignified manner.

Ethical considerations and awareness on behavior and power imbalances are integral to the training and screening of all candidates. All field researchers are selected through an intensive orientation day and trained in Level 1 training as a pre-requisite before undertaking any study. In the Level 1 training course there is a specific module on Ethical Standards and Considerations which covers: intervening; data protection policy; and household compensation.

All researchers sign Empatika's Code of Conduct on Confidentiality and the Child Protection Policy declarations as part of their contracts. In addition, all researchers sign the Study Confidentiality and Research Data Protection Declaration which ensures that all data (written and visual) is coded to protect the identity of individuals, their families and communities and photos and locations are kept confidential. In alignment with the UNICEF ethical procedures on 'Privacy and Confidentiality', the anonymity and privacy of all households and locations is ensured and researchers are obligated to not disclose locations even to family and friends. Special measures are taken to avoid inadvertent disclosure on social media. All data is coded and archived, and no identifiers retained in the archive. The archive is only accessible to the core team to ensure all data is kept confidentially. Storing all physical study materials in a secure location in the Empatika office, and all electronic materials on secure Empatika storage devices also increases the security of this data. In addition, in the one day study briefing prior to any study, all researchers are briefed again on ethical considerations (irrespective of whether they have previously gone through this).

In addition to the explanation that their participation is voluntary, study participants are also informed that they will receive no material benefits for participating. However, families/households we live with will receive a small amount of in-kind compensation from the researcher upon leaving to contribute to any expenses incurred; this will include items such as rice, salt, sugar, cooking oil (as culturally appropriate). This gift is in no way intended as a reward for participation in the study – it is not agreed upon at the outset or mentioned to the study participants until the researcher is leaving the community. Compensation is given in a way that is in alignment with UNICEF's Procedures relating to Payment and Compensations (2015) and is respectful to the role the households play and is made to ensure no loss of face and is low key.

Empatika undertakes a thorough risk assessment for the study locations in order to ensure the safety and security of the research team and participants. For safety and security measures, researchers are trained to identify potential risks, including child protection issues, and briefed on a series of procedures on how to respond to an emergency situation involving researchers and study participants. In every study location/s, a senior researcher/supervisor will lead the subteam and be the main contact person in case of emergency.

Prior to any fieldwork, each team conducts a risk matrix analysis for the particular area they are planning to live in, through desk review and local networks to identify and assess risks within that locality and prepare appropriate preventive measures to mitigate such risks.

#### **United Nations Children's Fund**

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