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A participatory study on community perspectives of zoonotic malaria (*Plasmodium knowlesi*) and malaria preventive behavior: A protocol paper

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Complete List of Authors:	Naserrudin, Nurul Athirah; Universiti Kebangsaan Malaysia, Department of Community Health Hod, Rozita; Universiti Kebangsaan Malaysia, Department of Community Health Saffree Jeffree, Mohammad ; Universiti Malaysia Sabah, Faculty of Medicine and Health Sciences Culleton, Richard; Ehime University Ahmed, Kamruddin; Universiti Malaysia Sabah, Department of Pathology and Microbiology, Faculty of Medicine and Health Sciences; Universiti Malaysia Sabah, Borneo Medical and Health Research Centre, Faculty of Medicine and Health Sciences Hassan, Mohd Rohaizat; Universiti Kebangsaan Malaysia, Department of Community Health
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4 1 **A participatory study on community perspectives of zoonotic malaria**
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11 4 Nurul Athirah Naserrudin^{1,3} Rozita Hod¹, Muhammad Saffree Jeffree^{2,4}, Richard Culleton⁶,
12
13 5 Kamruddin Ahmed^{2,5} and Mohd Rohaizat Hassan¹
14

15 6 ¹ Department of Community Health, Faculty of Medicine, Universiti Kebangsaan Malaysia, Cheras,
16
17 7 Kuala Lumpur, Malaysia
18

19 8 ² Borneo Medical and Health Research Centre, Faculty of Medicine and Health Sciences, Universiti
20
21 9 Malaysia, Sabah, Kota Kinabalu, Malaysia
22

23
24 10 ³ Sabah State Health Department, Ministry of Health, Kota Kinabalu, Malaysia
25

26 11 ⁴ Department of Community and Family Medicine, Faculty of Medicine and Health Sciences,
27
28 12 Universiti Malaysia Sabah, Kota Kinabalu, Malaysia
29

30 13 ⁵ Department of Pathobiology and Medical Diagnostics, Faculty of Medicine and Health Sciences,
31
32 14 Universiti Malaysia Sabah, Kota Kinabalu, Malaysia
33

34 15 ⁶ Division of Molecular Parasitology, Proteo-Science Centre, Ehime University, Japan
35
36
37 16

38
39 17 Corresponding author:

40
41 18 Mohd Rohaizat Hassan
42

43 19 Department of Community Health, Faculty of Medicine, Universiti Kebangsaan Malaysia, 56000
44
45 20 Cheras, Kuala Lumpur, Malaysia
46

47 21 Email: rohaizat@ppukm.um.edu.my
48
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51 23 **Keywords:** *Plasmodium knowlesi*, Participatory research, Photovoice, Focus group
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53 24 discussion, In-depth interview, Exploratory study, Malaria, Preventive behavior
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Abstract

Introduction: *Plasmodium knowlesi* malaria is a zoonotic mosquito-borne disease with complex epidemiology. We describe a participatory research (PR) design for a study aimed at exploring the social context and malaria preventive behavior of communities exposed to *P. knowlesi* malaria. According to the World Health Organization (WHO), the prevention and control of vector-borne diseases requires community participation to increase the coherence between malaria interventions and sustaining the public health programs.

Methods: The PR will be conducted over a period of 12 months, from March 2022 to March 2023, among adults (>18 years old) who are permanent residents in a rural village exposed to *P. knowlesi* malaria in Sabah, Malaysia. We will select patients who were diagnosed with *P. knowlesi* infection within January to December 2021 for the focus group discussion (FGD), as they can provide perspectives on disease from the point of view of those previously diagnosed with infection. In-depth interviews (IDI) with people of importance in the community, such as the head of the village will also be conducted. Both FGD and IDI will be conducted from March 2022 until June 2022. Concurrently, a photovoice with adults over 18 years old who reside in the community will be conducted. All participants will provide consent prior to participation. We will use a study framework as a theoretical lens to guide the exploration of the beliefs, social contexts, barriers, and drivers surrounding zoonotic malaria preventive behavior.

Discussion: The participatory approach can facilitate policymakers in designing future zoonotic malaria control programs by investigating the community perspectives and concerns about zoonotic malaria from a local context.

Ethical and dissemination: The study has ethical approval by NMRR/MREC and Universiti Kebangsaan Malaysia Research.. The results will be published in international peer-reviewed journals and presented at conferences and other platforms.

Strengths and limitations of the study

- The participatory approach protocol is geared toward conducting a research process with the adult > 18 years old in communities exposed to *P. knowlesi* malaria in Sabah, Malaysia to facilitate policymakers in designing future zoonotic malaria control programs
- The PR method will use a theoretical framework that integrates three models as a lens to guide the study
- The PR aims to create collaboration between researchers and participants, answer specific research questions, facilitate communication, and enable knowledge acquisition in a natural setting
- The study will use a participatory approach to explore the challenges of the communities to practise malaria preventive behaviour against zoonotic malaria in their local settings
- To build trust with participants, researchers require sufficient time, competencies, skills, and a high degree of flexibility and reflexivity throughout the study

68 Introduction

69 Since 2020, the World Health Organization (WHO) has included *Plasmodium knowlesi*
70 malaria in its World Malaria Report [1]. The increasing incidence of *P. knowlesi* malaria
71 among humans is a public health concern [1]. Malaria generally affects poor communities
72 with low levels of education and limited access to health services [1, 2]. Individuals working
73 as planters, farmers, or agricultural workers who may come into contact with macaques and
74 *Anopheles* mosquitoes are at risk of *P. knowlesi* malaria [3-5]. Ecological changes due to
75 deforestation and other anthropogenic activities increase the risk of zoonotic malaria [3-5].
76 Adults males are typically at higher risk than women and children, in particular individuals
77 who work in or visit forested areas [2, 5].

78 Vector control measures such as insecticide-treated nets (ITNs) and long-lasting
79 insecticide nets (LLINs) are used to control the incidence of malaria [1-6]. However, the
80 suitability of preventive measures such as protective clothing and bednets was perceived as
81 "uncomfortable" by individuals who worked in the forest [7]. Close proximity housing to the
82 forest increases the exposure of women and children to zoonotic malaria infection, leading
83 to their asymptomatic carriage of *P. knowlesi* malaria parasites [5]. Further research that
84 focuses on human behavioral factors that contribute to disease transmission is warranted [5,
85 8].

87 Malaria control strategy: socio-context and human behavior

88 Based on the UNDP/World Bank/WHO Special Programme for Research and Training in
89 Tropical Diseases (TDR), understanding the behavior of members of a community and its
90 socio-contexts can inform preventive measures [2]. People have difficulty understanding the
91 complexity of the epidemiology of zoonotic malaria [3, 12]. Quantitative surveys often fail to
92 account for the underlying causes of human behavior [8], and social contexts such as lifestyle,

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3 93 socio-cultural belief, economic factors, and behavioral factors can influence malaria exposure
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6 94 and usage of preventive measures [7-11], social gatherings and activities before bedtime
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8 95 increase the risk of mosquito bites [9]. Furthermore, ITNs are not effective when communities
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10 96 do not use them properly [7, 9]. In addition, cultural and economic activities also affect the
11
12 97 acceptance and usage of malaria preventive measures [7, 9], and can influence health-
13
14 98 seeking behaviors and compliance with preventive measures [2]. Malaria exposure is highest
15
16
17 99 for communities living in rural areas, and low-income households [1, 2], and these high risk
18
19 100 and marginalised communities require urgent complementary antimalarial measures that
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21
22 101 help them to avoid outdoor biting mosquitoes [2, 6].

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24 102 Numerous previous studies have been conducted on local beliefs concerning illness
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26 103 in different regions of the world [2, 7, 10]. In Indonesia, belief in a supernatural cause of
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28
29 104 malaria influences individuals to consume certain foods, use pendants, and "*jampi*" (magic).
30
31 105 They apply these measures rather than implementing evidence-based antimalarial measures
32
33 106 or seeking treatment at healthcare centers [7]. Individuals seek treatment with traditional
34
35
36 107 practitioners because of cost, and claim that these are more effective and reliable [2, 7].

37
38 108 Studies from Africa, Indonesia and the Philippines suggest that cultural and religious
39
40 109 beliefs influence understandings of the causation of malaria [2, 7, 9]. These beliefs impact on
41
42 110 adherence to bednet usage and influence attitudes towards health seeking behavior [2, 7].
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45 111 Understanding how communities perceive malaria and preventive measures such as bednet
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47 112 compliance can inform future malaria control programs [2, 6]. Along with understanding
48
49 113 community behavior, existing traditional knowledge should also be assessed prior to the
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51
52 114 design and implementation of malaria control strategies. For a program to be sustainable, the
53
54 115 community should be involved in its planning, implementation, and evaluation [2, 6]. Rather
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56 116 than focusing on the individual, community empowerment helps to increase the sustainability
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59 117 of interventions [2, 6]. As one of the pillars of a multisectoral approach to vector borne disease
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3 118 control, community participation is a powerful component that is cost-effective, practical, and
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6 119 facilitates behavioral changes that focus on enhanced vector control measures [6].
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8 120 The failures of "one size fits all" strategies for malaria control have prompted a re-
9
10 121 evaluation of the importance of communities' local priorities and needs [2, 6]. For example,
11
12 122 participatory research approaches can be used to explore the influence of social context on
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15 123 the surrounding environment as well as community behaviors that increase exposure to
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17 124 zoonotic malaria. It is crucial to investigate and explore opportunities for improving malaria
18
19 125 disease control. This will assist acceptance in local communities [6].
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22 126 Participatory research (PR), also known as 'community-based PR' and 'community
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24 127 research' [11] is a collaborative and iterative research design involving input from researchers
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26 128 and participants. It focuses on research processes that involve local people. PR incorporates
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29 129 community perspectives and emphasises the direct engagement of local priorities [11]. PR
30
31 130 differs from participatory action research (PAR) by shifting the emphasis from action and
32
33 131 changing to collaborative research activities [11]. PR aims to produce knowledge in
34
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36 132 collaboration between researchers and participants. This can lead to new insights [11]. The
37
38 133 advantage of PR is that researchers can conduct systematic inquiries with participants to
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40 134 gather local knowledge and experience from those who are immediately affected by the
41
42 135 ongoing issues [11]. This approach provides findings that may facilitate social change, and
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44
45 136 these changes can then be translated into action [11].
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49 138 **The characteristics of the participatory approach**

50
51 139 Discrete differences exist between PR and other research methodologies [11]. For example,
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53
54 140 in PR studies, power lies with the participants. It emphasises a "bottom-up" approach by
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56 141 incorporating local knowledge in future planning and program implementation [11]. In
57
58 142 contrast, other research designs often aim to generate knowledge from research without
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3 143 incorporating local priorities and perspectives. This oversight may result in inappropriate
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6 144 recommendations [11]. PR is an alternative approach for empowering, engaging, and
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8 145 creating a cohesive and sustainable vector control program. Such a program addresses local
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10 146 issues. Below we describe the methods that will be used and the analyses that will be
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12
13 147 conducted in this study.

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17 18 149 **Study perspective and health behavior model**

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20 150 From a constructivist perspective, the meaning and experience of phenomena are socially
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23 151 constructed, for example by social norms, beliefs, and environment, rather than inherent
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25 152 within individuals. This paradigm emphasises the generation of understanding an issue "from
26
27 153 the bottom up" [12]. Therefore, this study seeks to incorporate an understanding of socio-
28
29 154 cultural contexts and their structural conditions on malaria preventative behavior among
30
31
32 155 individuals and communities exposed to *P. knowlesi*. Previous studies have shown that
33
34 156 individuals and communities have their own native and socio-cultural beliefs toward the
35
36 157 disease and that these influence malaria preventive behavior [2]. There are also drivers and
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38
39 158 barriers to malaria preventative behavior in the community [2]. Participants in the study can
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41 159 provide local perspectives on preventive measures [2, 7], and opinions for future
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43 160 improvement of communication methods and tools to deliver preventative messages [2, 6].

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47 48 162 **The study framework**

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50 163 The study framework will integrate the ideation model [13], the explanatory model [14], and
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52 164 Murdock's illness causal model [15]. This framework will act as a theoretical lens for
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55 165 knowledge processing in this study. Theory can convey a clear signpost of the study and
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57 166 provide guidance on how and what method will help to answer the research questions [33].
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3 167 The ideation model is a predictive model of behavior change involving both individuals
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6 168 and communities. It is a socioecological approach involving communication and behavior
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8 169 change that integrates multiple theories [16, 17]. The ideation model acts as a conceptual
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10 170 tool that can identify common psychosocial variables that may influence malaria related
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13 171 behavior [13, 16, 17]. This framework identifies a set of psychosocial variables grouped into
14
15 172 three domains: cognitive, social support and emotion; (i) cognitive: attitudes towards the
16
17 173 recommended behavior, perceived risk and self-efficacy to protect self and others; (ii)
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19 174 emotional: feelings of fear relating to the condition that influences the intention of performing
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21
22 175 the behavior (iii) social: social support and peer pressure to practice or avoid the
23
24 176 recommended behavior and interpersonal communication with others about recommended
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26 177 practices [13, 16, 17].
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28
29 178 The explanatory model is a tool for medical and public health professionals to
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31 179 investigate cultural variations in illness experiences, diagnosis, and treatment. The model
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33 180 aids in developing rapid assessments through direct communication with patients, family
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36 181 members, and relatives [8, 14]. The data produced can facilitate the translation of
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38 182 interventions that consider the local perceptions of illness, circumstances that result in a risk
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40 183 pattern, and community structures that might support the intervention [8, 14].
41

42 184 Murdock's illness causal model conceptualised the local perception of causation of
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45 185 disease [15]. According to this theory, it is important to distinguish between beliefs about
46
47 186 natural and supernatural causes of illness, which are diverse worldwide, as they influence
48
49 187 how disease treatment and behavior are perceived [10, 15]. This framework has not been
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52 188 applied to research on *P. knowlesi* malaria to date.
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Study aim

This study aims to explore the key anthropological drivers of and barriers to zoonotic malaria preventative behavior among communities exposed to *P. knowlesi* infection. This study will be conducted among adults (age > 18 years old), including those with a history of *P. knowlesi* malaria infection, and those who live in areas with a high incidence of infection.

The study will address the primary research question: “According to adults (age > 18 years old), including those with past history of this infection, and live in an area exposed to *P. knowlesi* malaria infection, how and why does their beliefs towards the disease, and social, cultural and environmental challenges, underlie the zoonotic malaria preventive behavior?”. We will then translate the views of the communities into information for policymakers. Thus, addressing the other research question: “How can the views and concerns of this communities on zoonotic malaria infection and its challenges to preventive behavior can be translated into information for future *P. knowlesi* malaria control programme?”.

Methods and analysis

Study location

This study will be conducted in Sabah, the second largest state in Malaysia after Sarawak. It has a high incidence of *P. knowlesi* malaria [19, 20]. Sabah covers 73,904 sq km, with an estimated population of 3.90 million in 2019 [21]. Geographically, Sabah is composed of a mix of mountainous regions, coastlines, and tropical rainforests. A study by Cooper *et al.* reported five districts in Sabah with a high incidence of *P. knowlesi* malaria; Ranau, Keningau, Tenom, Tambunan, and Kota Marudu [22]. The present study will be conducted in the northern region of Sabah in Kudat region, the location of several recent studies on zoonotic malaria [3, 5, 23]. This district has a high incidence of *P. knowlesi* malaria, defined as >

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2
3 214 1/1000 persons [24]. This location was selected after obtaining a list districts with village
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6 215 names from the Sabah State Health Department, within areas with high incidences of *P.*
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8 216 *knowlesi* in 2020. (see Figure 1)
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10 217 11 12 218 **Study participants**

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15 219 The study participants will be men and women above 18 years old who can provide informed
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17 220 consent prior to the focus group discussion (FGD), in-depth interview (IDI), and photovoice.
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19 221 The study will include participants who are permanent residents of the village, are mobile,
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22 222 without known cognitive or mental health issues, and are able to answer questions in Malay
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24 223 or English. Due to restrictions imposed by the current COVID-19 pandemic, participants with
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26 224 access to electronic communication tools will be preferred [25, 26]. The sampling method for
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29 225 the FGD will be purposive sampling among individuals who were previously diagnosed with
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31 226 *P. knowlesi* infection between January 2021 and December 2021. It will consider the need to
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33 227 conduct discussions *via* electronic communication if there are restrictions against direct
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36 228 fieldwork. Community leaders will be selected for IDI. Subsequently, a snowballing technique
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38 229 will be used to recruit other information-rich individuals. The FGD and IDI method is planned
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40 230 for the four months from March 2022 through to June 2022. For the photovoice, a recruitment
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42 231 pamphlet will be distributed in the village, and we will use purposive sampling to recruit the
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45 232 participants. Similar to the FGD, individuals with good electronic connectivity will be preferred
46
47 233 in order to facilitate remote discussions in adherence with COVID-19 restrictions. Excluded
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49 234 from the study will be non-residents, people with known cognitive or mental health issues,
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51
52 235 and those who are unable to attend interviews or FDGs after two invites. All these methods
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54 236 will be conducted concurrently (between March and June 2022).
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3 **238 Sample size**
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6 239 For FGDs, 8 to 10 participants will be enrolled [27], while IDI may be up to 12 participants
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8 240 [28]. Data will be collected until data saturation is reached [27-29]. To maintain homogeneity
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10 241 of the FGD groups, participants will be stratified into gender and age-specific groups [27]. For
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12 242 example, males and females over 18 years old will be in different FGD groups to males and
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14 243 females over 65 years old. Earlier studies using photovoice methods reported enrolling four
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17 244 and up to 122 participants [30]. We aim to recruit 10 to 15 participants.
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22 **246 Categorisation of participation**
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24 247 The gradation of participation in this study is informed by Arnstein's categorisation, termed a
25
26 248 "ladder of citizen participation" [31]. This ladder distinguishes three main participation
27
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29 249 categories: citizen power, tokenism, and non-participation; and eight levels: manipulation,
30
31 250 therapy, informing, consultation, placation, partnership, delegated power, and client control
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33 251 [31]. We will utilise tokenism in our study. During the FGD, IDI, and photovoice methods, we
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35
36 252 will ensure that communication between researchers and participants allows them the
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38 253 opportunity to influence the decisions [31]. To ensure meaningful "tokenism" between
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40 254 researchers and participants in the photovoice method, we will provide a training workshop
41
42 255 and an introduction prior to commencing. The workshop will ensure a safe working
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45 256 environment, and agreements will be reached between the researchers and participants [32,
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47 257 33]. During the photovoice progress, we will regularly discuss the conditions for cooperation
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49 258 with the participants. The research questions will be shared with participants [32-34]. We will
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52 259 communicate in a clear manner in the Malay language and tailor communication to the
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54 260 literacy and coping level of the participants. The participants will receive a "token" for
55
56 261 participating in the study. Participants will have the right to withdraw from the study at any
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59 262 point.
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Study design

The study is a multimethod design using the PR approach. This study will be conducted over a 12 months period. The study will use FGD, IDI, and the photovoice method, which offers the advantage of triangulating the data (Figure 2). The views of individuals above 18 years old will be compared and interpreted with participants with a history of *P. knowlesi* infection. The photovoice method will raise their concerns using an iterative and collaborative process. Due to the COVID-19 pandemic, research methods may be modified to accommodate social distancing requirements [25, 26].

The study will have semi-structured interview guides. Rapport will be established with individuals so that topics can be freely discussed. Lastly, the study will use a participatory visual method (PVM); the photovoice. The researchers' role will be to introduce the research, the technique of photography, create a dialogue with participants (co-researchers), and conduct an exhibition or otherwise share the results with policymakers [32, 33].

The study phases

Phase 1: Preparation

The first phase of the study is to conduct a systematic literature review to understand: i) the behavior or activities that expose humans to *P. knowlesi* infection, and ii) how data on behavior were collected in previous studies. The literature searched was from standard scientific databases. The article abstracts were screened and assessed by three researchers, and any disagreement on the quality of the studies was resolved by consensus. The Joanna Briggs Institute critical appraisal checklist was used to rate the quality of the studies. A gray literature search was also performed from the WHO website.

The next step was to develop a research framework that would function as the theoretical lens for this study. The theoretical lens is the study's assumptions that will guide

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2
3 288 the study methodology. This framework focused on factors that possibly influence malaria
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6 289 preventative behavior. The third stage will be selection of participants. A pamphlet will be
7
8 290 distributed in the village to recruit participants for the photovoice project. Only those
9
10 291 individuals who show interest and match our eligibility criteria will be recruited. The
11
12 292 photovoice participants will attend a workshop introducing the study, discussing ethical
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15 293 considerations, distributing tasks, and outlining responsibilities. Participation will continue
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17 294 throughout the study duration.

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21 **Phase 2: Implementation of the study**

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24 297 The implementation of the study is as follows: FGD and IDIs will be conducted with
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26 298 participants to answer the specific research questions. Participants will participate in
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29 299 discussions and undergo an interview using the research questions as a guide. Data will be
30
31 300 collected and analysed by the research team. Both FGD and IDIs will be recorded,
32
33 301 transcribed *verbatim* by the research team, and analysed using thematic analysis [35]. We
34
35 302 will use the qualitative software program ATLAS.Ti Version 9.

36
37
38 303 The FGD and IDI will be performed in a place familiar to the participants. The FGD will
39
40 304 start with a general question about what participants perceive about *P. knowlesi* infection,
41
42 305 explore their beliefs concerning illness causation, and how and why these beliefs influence
43
44
45 306 their malaria-preventative behavior. Prompts will also be used to gather information and to
46
47 307 generate the codes and themes. The FGD will be conducted for approximately 90 minutes,
48
49 308 preferably without breaks [27]. The session will continue until a clear pattern emerges and
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51
52 309 subsequent groups do not produce new information [27-29]. Semi-structured, in-depth
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54 310 interviews will be conducted individually using an interview guide. Potential key informants,
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56 311 such as people of influence in the community [36], such as the head of village and faith

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3 312 leaders will be contacted by formal letter. A meeting will be arranged with this gatekeeper to
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6 313 build rapport and to request permission to conduct the study at the site [37].
7

8 314 Face-to-face interviews or modified interviews may be conducted using electronic
9
10 315 communication depending on the COVID-19 situation. The duration of the interview will be
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12 316 approximately 60-90 minutes [27]. The session will be written and recorded. As a means to
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15 317 maintain trustworthiness, member-checking and external coding will be used to validate the
16
17 318 interpretation and coding [38]. Interviews will continue until data saturation is reached [27-
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19 319 29].
20

21
22 320 In the photovoice method, participants will take photographs, discuss them through
23
24 321 the FGD method, and select the photos that best reflects the community [39-42]. Photovoice
25
26 322 research teams will work as closely as possible with the local structures and institutions to
27
28
29 323 facilitate meaningful long-term participation. The goals, strategies, and limitations for social
30
31 324 change will be clearly and realistically defined and communicated to avoid raising the
32
33 325 expectations of participants [41, 42]. The participants will have specific rules; such as prior
34
35 326 consent before taking pictures of adults and avoiding pictures of children. A WhatsApp group
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37
38 327 will be created by the researchers through which the participants will be encouraged to share
39
40 328 the photos. The photographs taken by the participants, that will be shared with policymakers
41
42 329 and the public, have value in that they provide the opportunity for virtual display when words
43
44
45 330 are difficult to express their views [24, 25, 32, 33]. Previous research suggests that
46
47 331 participants take an average of 50 photos each [42]. We will recommend 10 photos per
48
49 332 participant. The photographs can be taken anywhere, such as the home, street, or other
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51
52 333 aspects of the participant's environment, target actions, places, and situations [24, 25, 32,
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54 334 33, 39]. We will use the SHOWED algorithm to reveal the participants' reflections of their
55
56 335 photos [32]. The narrative caption of the photos will reveal meaningful experiences that can
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58 336 improve awareness of relevant issues [32, 33, 39].
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Phase 3: Dissemination

Due to the ongoing COVID-19 epidemic and resulting restrictions, we will look for opportunities to present the research findings on appropriate platforms, apart from the photos produced in the photovoice study, which will be exhibited [39]. Thus, dissemination will be through online research presentations, various scientific presentations, and a book [39]. The book will include coloured photos and narratives from participants that illustrate their perspectives on local beliefs, and the drivers and barriers to malaria preventative behavior. All the photovoice participants, including those that contribute photos will be given an opportunity to review the initial draft. Hardcopies will be disseminated to policymakers (for example the Sabah state health department).

Supervisory committee

The supervisory committee will monitor the study process, from initiation to the end of the study, and provide advice on the content of the study and its appropriateness with respect to the study aims. Monthly meetings are planned, and members of the supervisory committee will be asked for further input, if needed. Researchers and stakeholders will be a part of this supervisory committee.

Patients and public involvement

Participants were not directly involved in the study design. However, the snowballing technique will involve the recruited participants, in which the participants of the FGD and IDI will only act as research participants, and the participants in photovoice will conduct the photography session, give inputs in analysis, and participate in the exhibition. The researchers will conduct the final reporting and dissemination plan of this research.

Data analysis

Data will be collected by the researcher and research assistants (RAs) proficient in the local language. The RA will be trained by senior researchers (public health specialists and anthropologists) and will be the observers, notetakers and translators. The RA will assist in transcribing the data from the local language into English. The data will be exported into ATLAS.Ti software Version 9 to facilitate data analysis.

Thematic analysis

Thematic analysis will be used to generate codes and themes from the data [35, 43]. Data familiarisation will be through re-reading the transcripts. Initial codes will be generated systematically across the whole data set. Themes will be identified within codes, and these themes will be named and defined. Prior to the writeup, a review of the themes will be conducted [35, 43].

Rigor and data trustworthiness

Rigor is defined as the demonstration of integrity and competence within a study [44]. Data trustworthiness will be gained through feedback from participants (credibility, dependability), checks by participants and policymakers (confirmability), and a thorough description of data collection and analysis (transferability) [38]. Member-checking will be performed after all sessions of the chosen methods are completed [38]. For example, after an IDI session is completed, a summary will be given to participants to confirm or comment on the researcher's understanding throughout the session, and to maintain data accuracy. It will provide the opportunity to modify errors or wrong interpretations [38]. External coding will increase the validity of the data.[38] The coding process will be individually applied to the IDI, FGD, and

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3 387 photovoice data. The data will be triangulated to answer the research questions (RQs); and
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6 388 the interpretation of the data will be enriched by triangulation, as well as by creating new
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8 389 themes [35, 43].
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12 391 **Reflexivity of the researcher**

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15 392 Reflexivity and subjectivity are important characteristics of qualitative studies using thematic
16
17 393 analyses [35, 43]. The PR method encourages a self-reflective, engaged, and self-critical role
18
19 394 among researchers [11]. The primary investigator (PI) in this study has 10 years of experience
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21
22 395 of working as a primary care medical practitioner in a rural district in Sabah, Malaysia. The
23
24 396 PI will be the "facilitator" or "moderator" to guide the discussion between participants [27, 37].
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28 398 **The study outcome**

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31 399 Community participation in research is critical for developing information, education, and
32
33 400 communication tools to produce and promote public health programmes [11]. The views and
34
35 401 reflections of the community in the study are relevant for culturally sensitive and effective
36
37
38 402 future malaria-intervention programs, and could result in sustained malaria interventions [6].
39
40 403 The outcome of this study will be used to inform the development of community-friendly and
41
42 404 appropriate communication tools [6]. This approach is viewed as an essential component of
43
44
45 405 ethical good practice in research. It brings community health benefits by increasing the
46
47 406 chances of success of an intervention [2, 6]. Intervention can be in the form of education,
48
49 407 reflection, and discussion [6, 41, 42].
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53 409 **Discussion**

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56 410 Efforts have been made to assess how PR can be an effective research methodology for
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59 411 malaria intervention. A PR project contributed to increasing knowledge and awareness on
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3 412 malaria in the community in the Philippines [24]. Many previous programs have failed
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6 413 because of a lack of genuine community participation and also of recognition of community
7
8 414 perceptions of illness and prevention [6]. Engaging communities has improved
9
10 415 communication tools for the promotion of effective and sustainable interventions, enhanced
11
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13 416 their relevance and feasibility, and improved data utilisation by all stakeholders [6]. We hope
14
15 417 to provide empirical evidence to help develop future zoonotic malaria control programs.
16
17 418 Community engagement and feedback in our research will increase the reliability and validity
18
19 419 of the study through local knowledge and theory based on experiences [2, 6, 33]. Participants
20
21
22 420 will be empowered when their views and voices are heard [32, 33, 39]. Future studies and
23
24 421 collaborations that combine PR and emphasise community participation will reinforce
25
26 422 additional knowledge and appropriate behavior changes [41].
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30 31 424 **Study limitation**

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33 425 It is possible that, we may encounter a lack of trust among community members with the
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36 426 study, due to the limitation of time and space to engage with the whole community members
37
38 427 due to the current COVID-19 pandemic. We will attempt to minimise this by establishing trust
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40 428 through early communication and engagement with the head of the village. Community
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42 429 members may be sceptical about participating in the study in case their opinions are
43
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45 430 considered invalid, thus a poor response rate in certain phases of this study may be
46
47 431 encountered. A qualitative study is not a generalisable design but has the potential to develop
48
49 432 an in-depth understanding of the community from a small number of participants. Due to
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52 433 differences in overall philosophy, assumptions, beliefs, decision-making, and values, conflicts
53
54 434 can arise between study members and different organisations.
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Conclusion

The PR has important implications for the sustainability and appropriateness of malaria interventions. The PR provides insights from local people to improve the quality of research and ensure validity. The use of PR in health research promises far-reaching changes. Changing the relationship between researchers and those who participate in the research involves a transformation of power and views of the issues that provokes a more flexible and reflexive process among researchers.

Ethical approval

This study has been approved by the Medical Research and Ethics Committee Ministry of Health Malaysia (NMRR ID-21-01980-JEH), and the Research and Innovation Secretariat, Faculty of Medicine, Universiti Kebangsaan Malaysia (FF-2021-462).

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Author contributions

NAN was the principal investigator responsible for the design of the study and study protocol. MRH was the coordinating investigator. RC, MSJ, RH, KA, and MRH contributed equally to the content of the study protocol with important intellectual revisions. NAN drafted the manuscript. All authors read and approved the final protocol manuscript.

Conflicts of interest

There are no conflicts of interest associated with this protocol.

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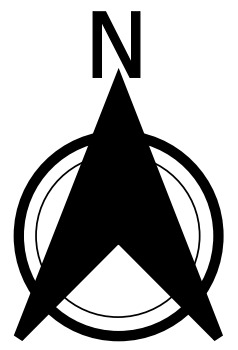
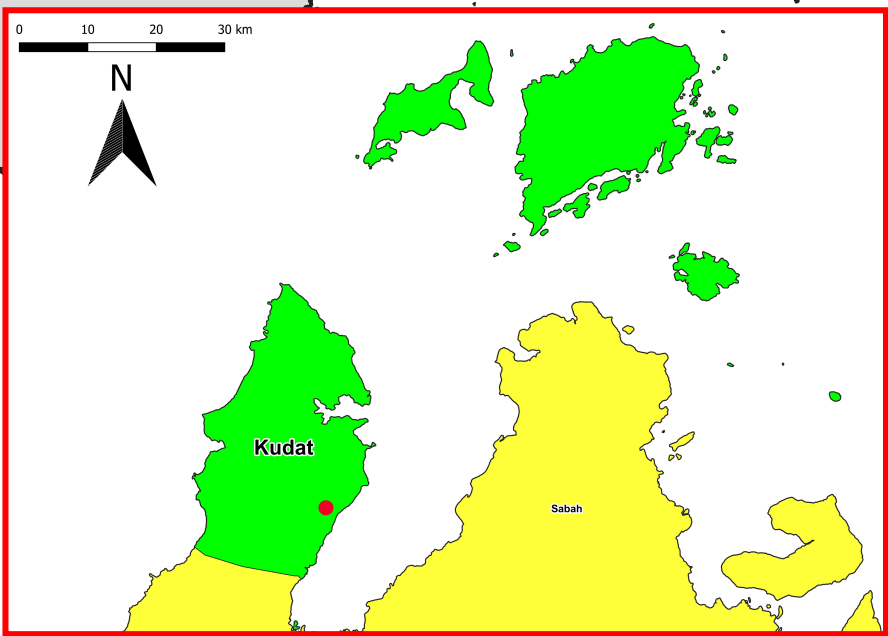
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Legend:

- Study Area
- Kudat District
- Malaysia Map



500 1,000 1,500 km

Study aim

To explore the beliefs and key anthropological drivers of and barriers to zoonotic malaria preventive behavior among communities exposed to *P. knowlesi* malaria infection

Methods

Focus group discussion
(*P. knowlesi* malaria cases > 18 years old, who were diagnosed between January to December 2021)

In-depth interview
(people of importance : head of village, traditional healers, etc)

Photovoice
(community members > 18 years old)

Analysis

Thematic analysis

Thematic analysis

1. Narrative caption of photographers
2. Thematic analysis of photovoice FGD

Result

Product Themes

Product Themes

- Products**
1. Themes
 2. Printed documents/book
 3. Exhibition

Discussion and conclusion

Study integration and inferences

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BMJ Open

Exploring the key anthropological drivers of and barriers to zoonotic malaria preventative behavior in a community exposed to Plasmodium knowlesi infection in Malaysia: protocol for a qualitative study with a participatory research design

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2022-060866.R1
Article Type:	Protocol
Date Submitted by the Author:	02-May-2022
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Primary Subject Heading:	Public health
Secondary Subject Heading:	Epidemiology
Keywords:	QUALITATIVE RESEARCH, INFECTIOUS DISEASES, Epidemiology < INFECTIOUS DISEASES, SOCIAL MEDICINE, Tropical medicine < INFECTIOUS DISEASES, Public health < INFECTIOUS DISEASES

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Manuscripts

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3 1 **Exploring the key anthropological drivers of and barriers to zoonotic**
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6 2 **malaria preventative behavior in a community exposed to *Plasmodium***
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9 3 ***knowlesi* infection in Malaysia: protocol for a qualitative study with a**
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16 6 Nurul Athirah Naserrudin^{1,2,3}, Richard Culleton⁴, Rozita Hod¹, Mohammad Saffree Jeffree^{2,5},
17
18 7 Kamruddin Ahmed^{2,6} and Mohd Rohaizat Hassan¹
19
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21 8

22
23 9 ¹ Department of Community Health, Faculty of Medicine, Universiti Kebangsaan Malaysia, Cheras,
24
25 10 Kuala Lumpur, Malaysia

26
27 11 ² Borneo Medical and Health Research Centre, Faculty of Medicine and Health Sciences, Universiti
28
29 12 Malaysia, Sabah, Kota Kinabalu, Malaysia

30
31 13 ³ Sabah State Health Department, Ministry of Health, Kota Kinabalu, Malaysia

32
33 14 ⁴ Division of Molecular Parasitology, Proteo-Science Centre, Ehime University, Japan

34
35 15 ⁵ Department of Public Health Medicine, Faculty of Medicine and Health Sciences, Universiti
36
37 16 Malaysia Sabah, Kota Kinabalu, Malaysia

38
39 17 ⁶ Department of Pathobiology and Medical Diagnostics, Faculty of Medicine and Health Sciences,
40
41 18 Universiti Malaysia Sabah, Kota Kinabalu, Malaysia
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43
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45
46 20 **Correspondence to:**

47
48 21 Mohd Rohaizat Hassan

49
50 22 Department of Community Health, Faculty of Medicine, Universiti Kebangsaan Malaysia, 56000

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52 23 Cheras, Kuala Lumpur, Malaysia

53
54 24 Email: rohaizat@ppukm.um.edu.my
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3 26 **Keywords:** *Plasmodium knowlesi* malaria, Participatory research, Photovoice, Interview,
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6 27 Exploratory study, Preventive behavior

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8 28 **Word count:** 5465
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For peer review only

ABSTRACT

Introduction: *Plasmodium knowlesi* malaria is a zoonotic mosquito-borne disease with complex epidemiology. According to the World Health Organization, the prevention and control of vector-borne diseases requires community participation to increase coherence between malaria interventions and sustainable public health programs. We describe a participatory research (PR) design for a study aimed at exploring the key anthropological drivers of and barriers to zoonotic malaria preventive behaviour among communities exposed to *P. knowlesi* infection in Malaysia. Participatory approaches can facilitate policymakers in designing future zoonotic malaria control programs by investigating community perspectives and concerns about zoonotic malaria in a local context.

Methods and analysis: The PR will be conducted over a period of 12 months, from March 2022 to March 2023, among adults (>18 years old) who are permanent residents in a rural village exposed to *P. knowlesi* malaria in Sabah, Malaysia. We will select patients who were diagnosed with *P. knowlesi* infection from January to December 2021 for focus group discussions (FGDs), as they can provide perspectives on disease from the point of view of those previously diagnosed with infection. In-depth interviews (IDIs) with people of importance in the community, such as village heads, will also be conducted. Both FGDs and IDIs will be conducted from March 2022 until June 2022. Concurrently, a photovoice with adults over 18 years old who reside in the community will be conducted. The target sample sizes for FGDs, IDIs and photovoice is 6-8, 12, and 10-15 participants, respectively. We will use a study framework as a theoretical lens to guide the exploration of the beliefs, social contexts, barriers, and drivers surrounding zoonotic malaria preventive behaviour.

Ethics and dissemination: This study has been approved by the Medical Research and Ethics Committee Ministry of Health Malaysia (NMRR ID-21-01980-JEH) and the Research and Innovation Secretariat, Faculty of Medicine, Universiti Kebangsaan Malaysia (FF-2021-

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3 54 462). All participants will provide consent prior to participation The results will be reported in
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5 55 international peer-reviewed journals and presented at conferences and on other platforms.
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10 57 **Strengths and limitations of this study**

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12 58 • The study will use a participatory approach to explore the challenges facing communities
13
14 59 practicing preventive behaviour against zoonotic malaria in their local settings.
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17 60 • The participatory approach protocol is geared toward conducting a research process with
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19 61 adults >18 years old in communities exposed to *Plasmodium knowlesi* malaria in Sabah,
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21 62 Malaysia to explore their perspectives on malaria and facilitate policymakers in designing
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23 63 future zoonotic malaria control programs.
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26 64 • The participatory research method will use a theoretical framework that has been
27
28 65 generated from expert consensus.
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31 66 • Qualitative studies are difficult to replicate in different settings and the results may not be
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33 67 relevant to other communities and larger populations.
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36 68 • The study is time-consuming and continuous engagement is needed with all community
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38 69 members in order to build trust with researchers.
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70 INTRODUCTION

71 In 2020, the World Health Organization (WHO) included *Plasmodium knowlesi* (*P. knowlesi*)
72 malaria in its World Malaria Report for the first time.[1] Since the first report of *P. knowlesi*
73 cases in Kapit, Sarawak, Malaysia in 2004, the parasite has been reported infecting people
74 in other countries throughout the South-East Asia region.[2, 3] The increasing incidence of
75 *P. knowlesi* malaria among humans is a possible public health threat in the future.[3] The
76 highest number of *P. knowlesi* cases in humans occur in Sabah and Sarawak states,
77 Malaysian Borneo.[4] Despite positive progress towards achieving elimination of human
78 malaria in Malaysia, the increasing incidence of *P. knowlesi* requires the application of interim
79 strategies to reduce its transmission.[3] The threat of zoonotic malaria infection has increased
80 dramatically, and thus it is critical to revisit current malaria control strategies and design
81 interventions specific to zoonotic malaria.[3]

82 In Sabah state, cases of *P. knowlesi* malaria infection increased from 100 cases per
83 year in the year 2000 to 1325 cases in 2014.[4] In 2018, there were 4131 reported *P. knowlesi*
84 cases throughout Malaysia, with the highest incidence rate of 0.13 cases per 1000
85 population.[4] Malaysia reported its last indigenous human malaria cases in 2017, with only
86 85 cases.[4] *P. knowlesi* malaria cases were commonly diagnosed in adult males and
87 persons who performed forest related work.[5] While majority of cases were uncomplicated,
88 fatalities were reported in patients as young as 31 years old.[6] Furthermore, the detection of
89 asymptomatic cases of *P. knowlesi* malaria in human populations, including in children and
90 within families, suggest potential target populations for interventions.[3, 7]

91 Malaria generally affects poor communities with low levels of education and limited
92 access to health services.[1] Individuals who may come into contact with macaques and
93 *Anopheles* mosquitoes are at risk of *P. knowlesi* malaria.[2-10] Ecological changes due to
94 deforestation and other anthropogenic activities increase the risk of zoonotic malaria.[8]

1
2
3 95 Zoonotic spillovers expose communities living in rural and semirural areas to *P. knowlesi*
4
5 96 malaria infection due to the destruction of the natural hosts' habitat. Macaque monkeys move
6
7
8 97 father from logging activities and favour human settlements.[9] In addition, *Anopheles*
9
10 98 mosquito vectors from the *Leucospyrus* group prefer to breed in muddy ground pools, swamp
11
12 99 water and water pockets.[10] Vectors may also breed in sites like bamboo stumps, tins and
13
14
15 100 other artificial containers.[10] The potential impact of this zoonotic spillover into vulnerable
16
17 101 communities requires interim strategies and multisectoral approaches for its prevention and
18
19 102 control.[7, 11]

20
21
22 103 In 1961, Malaysia launched its Malaria Eradication Program.[12] Various vector control
23
24 104 measures were introduced including indoor residual spraying (IRS) and the distribution of
25
26 105 insecticide treated bednets (ITNs).[12] The provision of free malaria tools has reduced human
27
28 106 malaria cases by 7-fold over 30 years.[4] Zoonotic malaria, however, may not be controlled
29
30
31 107 to the same degree as human-restricted malaria due to the different factors that control its
32
33 108 transmission.[5] Exacerbating this problem, persuading the local populations to adopt
34
35 109 different control measures for what they perceive as the same problem is difficult. In
36
37
38 110 Indonesia, for example, zoonotic-malaria specific preventive measures such as protective
39
40 111 clothing and bednets were perceived as "uncomfortable" by community members.[13] Among
41
42 112 the indigenous tribes people of Peninsular Malaysia, there is a belief that malaria has a
43
44
45 113 supernatural origin, causing the community to perceive zoonotic malaria differently.[14].
46
47 114 Further research that explores the social context and human related factors that contribute
48
49 115 to disease transmission is warranted.[5]

50 51 52 116 53 54 117 **Malaria control strategy: socio-context and human behaviour**

55
56 118 Based on the UNDP/World Bank/WHO Special Programme for Research and Training in
57
58 119 Tropical Diseases (TDR), understanding the behaviour of members of a community and its
59
60

1
2
3 120 socio-contexts can inform preventive measures.[15] Quantitative surveys often fail to account
4
5
6 121 for the underlying causes of human behaviour that lead to exposure to health risks.[15, 16]
7
8 122 Furthermore, social contexts such as lifestyle, socio-cultural belief, economic factors, and
9
10 123 behavioural factors can influence malaria exposure and the usage of preventive measures.[3,
11
12 124 15-17] Social gatherings and other activities that are performed before bedtime can increase
13
14
15 125 the risk of mosquito bites.[18-20]. Furthermore, ITNs are not effective when communities do
16
17 126 not use them throughout the night.[19] *P. knowlesi* vectors are typically exophagic, exophilic
18
19 127 and bite early during the night-time, thus indoor-based interventions are unlikely to provide
20
21
22 128 sufficient protection.[10] Recently, mosquitoes of the *Umbrosus* group were found to bite
23
24 129 early (from 11:00 in the afternoon), thus increasing the risk to communities performing day-
25
26 130 time activities.[20] In addition, cultural and economic activities also affect the acceptance and
27
28
29 131 usage of malaria preventive measures.[5] Farming communities and agricultural sector
30
31 132 workers in oil palm farm and rubber estates were non-complaint with preventive measures
32
33 133 due to various factors such as inconvenience and low perceive threat.[5, 13] These
34
35
36 134 populations are at high risk to exposure to *P. knowlesi* malaria and thus complementary
37
38 135 antimalarial strategies are required.[3, 7, 21]. For example, the One Health initiatives enforce
39
40 136 ecological regulations that limit deforestation.[21] *P. knowlesi* malaria control measures
41
42 137 should integrate a transdisciplinary approaches through identification of the risks of vector-
43
44
45 138 human contact during outdoor activities.[5, 7, 21]

46
47 139 Numerous previous studies have been conducted on local beliefs concerning malaria
48
49 140 in different regions of the world.[14, 22-24] In Indonesia, belief in a supernatural cause of
50
51
52 141 malaria influences individuals to consume certain foods and to use pendants and "*jampi*"
53
54 142 (magic). They apply these measures rather than implementing evidence-based antimalarial
55
56 143 measures or seeking treatment at healthcare centres.[13] Individuals seek treatment with
57
58
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1
2
3 144 traditional practitioners because of cost, and claim that these are more effective and reliable.
4
5
6 145 [13, 25]

7
8 146 Studies from Malaysia, Africa, Indonesia, India and the Philippines suggest that
9
10 147 cultural and religious beliefs influence understandings of the causation of malaria.[15, 23-25]
11
12 148 These beliefs impact on adherence to bednet usage and influence attitudes towards health
13
14 149 seeking behaviour. Understanding how communities perceive malaria and preventive
15
16
17 150 measures such as bednet compliance can inform future *P. knowlesi* malaria control
18
19 151 programs.[3] Along with understanding community behaviour, existing traditional knowledge
20
21
22 152 should also be assessed prior to the design and implementation of *P. knowlesi* malaria control
23
24 153 strategies.[3] For a program to be sustainable, the community should be involved in its
25
26 154 planning, implementation, and evaluation.[11, 15] Rather than focusing on the individual,
27
28 155 community empowerment helps to increase the sustainability of interventions.[11] As one of
29
30
31 156 the pillars of a multisectoral approach to vector borne disease control, community
32
33 157 participation is a powerful component that is cost-effective, practical, and facilitates
34
35 158 behavioural changes that focus on enhanced vector control measures.[11]

37
38 159 The failures of "one size fits all" strategies for malaria control have prompted a re-
39
40 160 evaluation of the importance of communities' local priorities and needs.[11, 15] For example,
41
42 161 participatory research approaches can be used to explore the influence of social context on
43
44
45 162 the surrounding environment as well as community behaviours that increase exposure to
46
47 163 zoonotic malaria. It is crucial to investigate and explore opportunities for improving malaria
48
49 164 disease control. This will assist acceptance in local communities.

51
52 165 Participatory research (PR), also known as 'community-based PR (CBPR)' or
53
54 166 'community research' is a collaborative and iterative research design involving input from
55
56 167 researchers and participants.[26] It focuses on research processes that involve local
57
58 168 people.[27, 28] The term is used interchangeably, thus throughout this protocol manuscript,
59
60

1
2
3 169 the term CBPR will be used. Israel *et al* described CBPR as a constructivist and critical
4
5
6 170 theoretical perspective that argues with positivist ideology.[28] Through CBPR, the findings
7
8 171 can facilitate improvements in health-related interventions, and generate evidence based
9
10 172 practices.[27, 28] CBPR incorporates community perspectives and emphasises the direct
11
12
13 173 engagement of local priorities.[27] CBPR differs from participatory action research (PAR) by
14
15 174 shifting the emphasis from action to collaborative research activities.[27, 28]

16
17 175 CBPR aims to produce knowledge through collaboration between researchers and
18
19 176 research participants.[27, 28] CBPR embeds the practice of knowledge democracy by using
20
21
22 177 multiple ways of exploring community knowledge through expressions such as local
23
24 178 narratives and songs.[27] This can lead to new insights regarding health research , and can
25
26 179 act as a tool for exploring social activity in relation to social action and health equity.[27]
27
28
29 180 Greater sensitivity to communities involving listening to their voices, can generate trust and
30
31 181 build partnerships and relationships between researchers and participants.[27] In CBPR
32
33 182 studies, both quantitative and qualitative methods can be used.[27] The advantage of CBPR
34
35
36 183 is that researchers can conduct systematic inquiries with study participants. Often these are
37
38 184 marginalized or disenfranchised communities, who are immediately affected by the ongoing
39
40 185 issues.[27, 28]

41 42 186 43 44 45 187 **Characteristics of the community-based participatory approach**

46
47 188 Discrete differences exist between CBPR and other research methodologies.[27] CBPR
48
49 189 democratizes participant knowledge by instilling the belief that people exert a positive
50
51
52 190 influence on their circumstances.[27] CBPR reduces the gap between theory, research and
53
54 191 practical recommendations.[27, 28] There are guidelines such as those described by Israel
55
56 192 *et al.*,[28] however each research is unique in that it is dependent on local issues.[27] For
57
58 193 example, CBPR studies emphasise a "bottom-up" approach by incorporating local knowledge
59
60

1
2
3 194 in future planning and program implementation.[27] The co-learning process between
4
5
6 195 researchers and participants facilitates reciprocal transfer of knowledge, skills and
7
8 196 capacity.[27] In contrast, other research designs often aim to generate knowledge from
9
10 197 research without incorporating local priorities and perspectives. This oversight may result in
11
12
13 198 inappropriate recommendations.[27, 28] CBPR also places an emphasis on the
14
15 199 empowerment of community members as co-researchers, by allowing the sharing of
16
17 200 information, decision making, and partnerships.[27] CBPR is an alternative approach for
18
19 201 empowering, engaging, and creating cohesive and sustainable vector control programmes
20
21
22 202 addressing local issues.[29] In the Philippines, through the Participatory Visual Method (PVM)
23
24 203 using photovoice methodology, researchers gained access to the live and social context of
25
26 204 the communities through images captured by the participants.[29] The images act as a
27
28
29 205 powerful tool to informed policymakers on communities' belief and preventive measures
30
31 206 against malaria, through the eye of community members.[29] Below we describe the methods
32
33 207 that will be used and the analyses that will be conducted in this study.
34
35

36 208 37 38 39 209 **Study perspective and health behaviour model**

40
41 210 From a constructivist perspective, the meaning and experience of phenomena are socially
42
43 211 constructed, for example by social norms, beliefs, and environment, rather than inherent
44
45 212 within individuals.[30] This paradigm emphasises the generation of understanding an issue
46
47
48 213 "from the bottom up" approach.[30] In CBPR studies, community involved in the research
49
50 214 through their participation in addressing the research inquiry, through discussion of the data
51
52 215 and interpretation of the findings. This process is valued and underpinned by the concept of
53
54
55 216 critical consciousness[31] and feminist theory.[32] Through this ideology, the Brazilian
56
57 217 educator Paulo Freire, proposed the concept of education through collective dialogue with
58
59 218 the oppressed and poor people.[31] In feminist theory, participants are able to participate in
60

1
2
3 219 the decision making process through the power that arises from the voice of people who live
4
5
6 220 within the issues.[32]

7
8 221 This study seeks to incorporate an understanding of socio-cultural contexts and their
9
10 222 structural conditions on malaria preventative behaviour among individuals and communities
11
12 223 exposed to *P. knowlesi* malaria. Previous studies have shown that individuals and
13
14 224 communities have their own native and socio-cultural beliefs toward the disease and that
15
16
17 225 influenced malaria preventive behaviour.[13-15] In addition, there are also drivers to and
18
19 226 barriers of malaria preventative behaviour in the communities.[15, 18, 19] Participants in the
20
21
22 227 study can provide local perspectives on their beliefs and preventive measures, and offer
23
24 228 opinions for future improvement of methods and tools to deliver preventative messages..
25

26 229

27 28 29 230 **Study framework**

30
31 231 The study framework will integrate the ideation model,[33] the explanatory model,[34] and
32
33 232 Murdock's illness causal model.[35] This framework will act as a theoretical lens for
34
35 233 knowledge processing in this study. Theory can convey a clear signpost of the study and
36
37
38 234 provide guidance on how and what method will help to answer the research questions.[30]
39

40 235 The ideation model is a predictive model of behaviour change involving both
41
42 236 individuals and communities.[33, 36] It is a socioecological approach involving the integration
43
44
45 237 of communication and multiple behaviour theories.[33, 36] The model acts as a conceptual
46
47 238 tool that can identify common psychosocial variables that may influence malaria related
48
49 239 behaviour [37-39] This framework identifies a set of psychosocial variables grouped into three
50
51
52 240 domains: cognitive, social support and emotion.[33] For example, cognitive variables or
53
54 241 factors include the attitude towards the recommended preventive behaviour, perceived risk
55
56 242 and self-efficacy to avoid malaria infection. While emotion, could described the feelings of
57
58 243 fear towards malaria infection. Social support variables or factors embrace the community
59
60

1
2
3 244 support and peer pressure to practice or avoid the recommended preventive behaviour.[37-
4
5
6 245 39]

7
8 246 The explanatory model is a tool for medical and public health professionals to
9
10 247 investigate cultural variations in illness experiences, diagnosis, and treatment.[34] The model
11
12 248 aids in developing rapid assessments through direct communication with patients, family
13
14
15 249 members, and relatives.[16, 34] The data produced can facilitate the translation of
16
17 250 interventions that consider the local perceptions of illness, circumstances that result in a risk
18
19 251 pattern, and community structures that might support the intervention.[16, 34]

20
21
22 252 Murdock's illness causal model conceptualised the local perception of causation of
23
24 253 disease.[35] According to this theory, it is important to distinguish between beliefs about
25
26 254 natural and supernatural causes of illness, which are diverse worldwide, as they influence
27
28
29 255 how disease treatment and behaviour are perceived.[35, 40]

30 31 256 32 33 257 **Study aim**

34
35
36 258 This study aims to explore the key anthropological drivers of and barriers to zoonotic malaria
37
38 259 preventative behaviour among communities exposed to *P. knowlesi* malaria infection. This
39
40 260 study will be conducted among adults (age > 18 years old), including those with a history of
41
42 261 *P. knowlesi* malaria infection, and those who live in areas with a high incidence of the
43
44
45 262 infection.

46
47 263 The study will address the primary research question: "According to adults (age > 18
48
49 264 years old), including those with past history of this infection, and who live in an area exposed
50
51
52 265 to *P. knowlesi* malaria infection, how and why do their beliefs towards the disease, and social,
53
54 266 cultural and environmental challenges, influence zoonotic malaria preventive behaviour?". In
55
56 267 view of the fact that current vector control measures do not protect against *Anopheles*
57
58
59 268 mosquito bites, we defined preventive behaviour as 'avoidance of mosquito bites'. We will
60

1
2
3 269 then translate the views of the communities into information for policymakers, thus
4
5
6 270 addressing the second research question: “How can the views and concerns of these
7
8 271 communities regarding zoonotic malaria infection inform future *P. knowlesi* malaria control
9
10 272 programme?”.

11
12
13 273

14 15 274 **METHODS AND ANALYSIS**

16 17 275 **Study setting**

18
19
20 276 This study will be conducted in the highly *P. knowlesi* endemic state of Sabah, Malaysia.[41]
21
22 277 Sabah covers 73,904 sq km, with an estimated population of 3.90 million in 2019.[42]
23
24 278 Geographically, Sabah is composed of a mix of mountainous regions, coastlines, and tropical
25
26
27 279 rainforests. In Sabah, *Anopheles leucosphyrus* group mosquitoes are the major vector for *P.*
28
29 280 *knowlesi* malaria infection.[43] A study by Cooper *et al.* reported five districts in Sabah with
30
31 281 a high incidence of *P. knowlesi* malaria; Ranau, Keningau, Tenom, Tambunan, and Kota
32
33
34 282 Marudu, which are located along the Crocker range.[44] The present study will be conducted
35
36 283 in the northern region of Sabah in Kudat region, the location of several recent studies on
37
38 284 zoonotic malaria.[8, 9, 43, 45] (figure 1).The incidence in Kudat district is estimated at 0.90
39
40
41 285 to 1.36 per 1000 population.[44] The location was selected after obtaining a list districts with
42
43 286 village names from the Sabah State Health Department, within areas with high incidences of
44
45 287 *P. knowlesi* in 2020.

46
47 288
48

49 50 289 **Study participants**

51
52 290 The study participants will be adult men and women (above 18 years old) who can provide
53
54 291 informed consent prior to the focus group discussions (FGDs), in-depth interviews (IDIs), and
55
56
57 292 photovoice. The study will include participants who are permanent residents of the village,
58
59 293 are mobile, without known cognitive or mental health issues, and are able to answer
60

1
2
3 294 questions in Malay or English language. Due to restrictions imposed by the current COVID-
4
5
6 295 19 pandemic, participants with access to electronic communication tools will be preferred.[46,
7
8 296 47] We anticipate the recruitment of participants with access to electronic communication
9
10 297 tools will cause bias in the study results. However, in view of the improved COVID-19 situation
11
12
13 298 in Malaysia and the ability to conduct fieldwork with strict Standard Operating Procedures
14
15 299 (SOPs), this bias may be minimized by conducting the study at the study sites and via face
16
17 300 to face interviews. The sampling method for the FGDs will be purposive sampling among
18
19 301 individuals who were previously diagnosed with *P. knowlesi* malaria infection between
20
21
22 302 January 2021 and December 2021. Community leaders will be selected for IDIs.
23
24 303 Subsequently, a snowballing technique will be used to recruit other information-rich
25
26 304 individuals. For the photovoice, a recruitment pamphlet will be distributed in the village, and
27
28
29 305 we will use purposive sampling to recruit the participants. Excluded from the study will be
30
31 306 non-residents, people with known cognitive or mental health issues, and those who are
32
33 307 unable to attend interviews or FDGs after two invites. All these methods will be conducted
34
35 308 concurrently for twelve months from March 2022 through to March 2023.
36
37
38 309

40 310 **Sample size**

41
42 311 For FGDs, 6 to 8 participants will be enrolled,[48] while the sample size fo IDIs may be up to
43
44
45 312 12 participants.[49] Data will be collected until data saturation is reached, defined as when
46
47 313 there is no new information collected from subsequent participants.[48, 49] Earlier studies
48
49 314 using photovoice reported enrolling between four and 122 participants.[50] We aim to recruit
50
51 315 10 to 15 participants.
52
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54 316
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1

2

3 317 **Categorisation of participation**

4

5 318 The gradation of participation in this study is informed by Arnstein's "ladder of citizen
6 participation" categorization.[51] This ladder distinguishes three main participation
7 categories: citizen power, tokenism, and non-participation; and eight levels: manipulation,
8 319 therapy, informing, consultation, placation, partnership, delegated power, and client
9 control.[51] We will utilise tokenism in our study. During the FGDs, IDIs, and photovoice, we
10 320 will ensure that communication between researchers and participants allows them the
11 opportunity to influence the discussion and analysis. However, those with power (e.g
12 321 policymakers) will have power over decisions.[51] For example, to ensure meaningful
13 "tokenism" between researchers and participants in photovoice, we will provide an
14 introduction and training workshop prior to commencing the method. The workshop will
15 322 ensure a safe working environment, and agreements will be reached between the
16 researchers and participants upon the methodology.[52, 53] During the photovoice progress,
17 323 we will regularly discuss the conditions for cooperation with the participants. The research
18 questions will be shared with participants.[53] We will communicate in a clear manner in the
19 324 Malay language and tailor communication to the literacy and coping level of the participants.
20 The participants will receive a "token" for participating in the study. Participants will have the
21 right to withdraw from the study at any point.

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70 373

47 336 **Study design**

48

49 337 The study is a multimethod design using the CBPR methodology.[27] This study will be
50 conducted over a 12 month period. Rapport will be established with individuals so that topics
51 338 can be freely discussed.[27] The study will use FGD, IDI, and the photovoice method, which
52 offers the advantage of triangulating the data. A semi-structured interview guides have been
53 prepared and approved by the research supervisory and ethical committees. The views of all

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55 340

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2
3 342 participants which will be recruited in different methods, will be compared and interpreted to
4
5
6 343 achieve data triangulation. The photovoice will raise their perspectives and concerns using
7
8 344 an iterative and collaborative process.[50, 54] The researchers' role will be to introduce the
9
10 345 research aims and questions to the participants. In view of study using the CBPR
11
12 346 methodology, the creation of discussion will be conducted through dialogues with participants
13
14
15 347 (co-researchers).[27] The dissemination of study findings with policymakers will either be
16
17 348 conducted through exhibition (e.g at local townhall) or different platforms (e.g colored book,
18
19 349 peer-reviewed manuscript, conference presentations).[53-55] (figure 2) However, due to the
20
21
22 350 COVID-19 pandemic, research methods may be modified to accommodate social distancing
23
24 351 requirements and other SOPs.
25

26 352 27 28 **Study phases** 29 353

30 31 354 Phase 1: Preparation 32

33 355 The first phase of the study is to conduct a systematic literature review to understand: i) the
34
35 356 behaviour or activities that expose humans to *P. knowlesi* malaria infection, and ii) how data
36
37
38 357 on behaviour were collected in previous studies.[5] The literature searched was from
39
40 358 standard scientific databases. The article abstracts were screened and assessed by three
41
42 359 researchers, and any disagreement on the quality of the studies was resolved by consensus
43
44
45 360 of the co-authors.[5] The Joanna Briggs Institute critical appraisal checklist was used to rate
46
47 361 the quality of the studies. A grey literature search was also performed from the WHO website.
48
49 362 It was found that the that majority of the included studies were done quantitatively, limiting a
50
51
52 363 deep understanding of human behaviour.[5] Several factors such as socioeconomic status,
53
54 364 beliefs, perceived threats, motivation, and coping issues can influence communities' malaria
55
56 365 preventive behaviour.[5] Future studies must consider using qualitative study designs in order
57
58
59 366 to generate a rich information and address how human behaviour can influence the exposure
60

1
2
3 367 to zoonotic malaria.[5] Furthermore, the importance of community perspective on *P. knowlesi*
4
5 368 malaria control is critical to strategize a specific *P. knowlesi* malaria control guidelines.[5, 7]
6
7

8 369 The next step was to develop a research framework that would function as the
9
10 370 theoretical lens for this study. The theoretical lens is the study's assumptions that will guide
11
12 371 the study methodology.[30] Using the modified Delphi study, new themes were generated
13
14
15 372 through the consensus of experts.[56] The experts were selected based on the inclusion
16
17 373 criteria as per the protocol.[56] Twelve experts were selected based on (I) having more than
18
19 374 five years of experience working or practicing in any research institutions, having an
20
21
22 375 administrative post in any organization and conducting malaria research, (II) individuals who
23
24 376 have published more than one study on malaria in peer-reviewed journals and (III) consented.
25
26 377 This framework focused on factors that possibly influence malaria preventative behaviour in
27
28
29 378 communities exposed to *P. knowlesi* malaria infection through the collective agreement
30
31 379 among the expert panels.[56] (figure 3).
32

33 380 The third stage will be selection of participants. A pamphlet using the Malay language
34
35 381 were distributed in the village to recruit participants for photovoice (figure 4). The distribution
36
37
38 382 were done after the meeting with the community leaders. Only those individuals who show
39
40 383 interest and match our eligibility criteria will be recruited. The purposive and convenience
41
42 384 sampling method will be used to avoid participants' dropouts. The photovoice participants will
43
44
45 385 attend a workshop introducing the study, discussing ethical considerations, distributing tasks,
46
47 386 and outlining responsibilities. Participation will continue throughout the study duration.[55]
48

49 387
50
51 388 Phase 2: Implementation of the study

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53
54 389 The implementation of the study is as follows: FGDs and IDIs will be conducted with
55
56 390 participants to answer the specific research questions. Participants will participate in
57
58 391 discussions and undergo interviews using the interview guides. Data will be collected and
59
60

1
2
3 392 analysed by the research team. The research team consists of epidemiologists, public health
4
5
6 393 specialists, medical anthropologists, infectious disease experts and a postgraduate student.
7
8 394 FGDs, IDIs, and photovoice will be recorded, transcribed *verbatim* by the research team, and
9
10 395 analysed using thematic analysis by Braun and Clark approach.[57]
11

12
13 396 The FGDs and IDIs will be performed in a place familiar to the participants.[58] The
14
15 397 FGDs will start with a general question about what participants perceive about *P. knowlesi*
16
17 398 malaria infection, explore their beliefs concerning illness causation, and how and why these
18
19 399 beliefs influence their malaria-preventive behaviour. Prompts will also be used to gather
20
21
22 400 information and to generate a richer data. The FGDs will be conducted for approximately 90
23
24 401 minutes, preferably without breaks.[58] The session will continue until a clear pattern
25
26 402 emerges and subsequent interviews do not produce new information.[57] IDIs will be
27
28
29 403 conducted individually using an interview guide. Potential key informants, such as people of
30
31 404 influence in the community, such as the head of village and faith leaders,[59] will be contacted
32
33 405 by formal letter, individually. A meeting has been arranged with this gatekeeper to build
34
35 406 rapport and to request permission to conduct the study at the site.[60]
36

37
38 407 Interviews will be conducted using face to face sessions, however electronic
39
40 408 communication may be warranted depending on the COVID-19 situation. The duration of the
41
42 409 interview will be approximately 60-90 minutes.[57, 58] The session will be written in fieldnotes
43
44
45 410 and recorded, audio and verbally. As a means to maintain data trustworthiness, member-
46
47 411 checking and external coding will be used to validate the data .interpretation and coding.[61]
48

49 412 In photovoice, participants will take photographs (e.g using camera or smartphones),
50
51
52 413 discuss them through the FGDs, and select the photos that best reflects the community for
53
54 414 future dissemination of study findings.[62, 63] Photovoice research team will work as closely
55
56 415 as possible with the local structures and institutions to facilitate meaningful long-term
57
58 416 participation.[62] The goals, strategies, and limitations for social change will be clearly and
59
60

1
2
3 417 realistically defined and communicated to avoid raising the expectations of participants.[54,
4
5
6 418 63] The photovoice participants will have specific rules; such as the requirement of consent
7
8 419 before taking pictures of adults and avoiding pictures of children. A WhatsApp group will be
9
10 420 created by the researchers through which the participants will be encouraged to share the
11
12
13 421 photos. The photographs taken by the participants, that will be shared with policymakers,
14
15 422 have value in that they provide the opportunity for virtual display when words are difficult to
16
17 423 express their views.[54, 62] Previous research described participants shared around 9-182
18
19 424 photographs and suggests that participants take an average of 40 to 50 photos each.[62] We
20
21
22 425 will recommend 10 photos per participant. The photographs can be taken anywhere, such as
23
24 426 the home, street, or other aspects of the participant's environment, target actions, places,
25
26 427 and situations.[55, 62, 63] We will use the SHOWeD algorithm to reveal the participants'
27
28
29 428 reflections of their photos.[63] The narrative caption of the photos will reveal meaningful
30
31 429 experiences that can improve awareness of relevant issues.[63]
32

33 430

35 431 Phase 3: Dissemination

37
38 432 Due to the ongoing COVID-19 epidemic and resulting restrictions, we will look for
39
40 433 opportunities to present the research findings on appropriate platforms. Thus, dissemination
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42 434 will not only be at the local townhall with the participants, but also through online research
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45 435 presentations, various scientific presentations, and a book.[55] The book will include coloured
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47 436 photos and narratives from participants that illustrate their perspectives on local beliefs, and
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49 437 the drivers and barriers to malaria preventive behaviour. All the photovoice participants, will
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52 438 be given an opportunity to review the initial draft. Hardcopies will be disseminated to
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54 439 policymakers (for example the Sabah State Health Department and Ministry of Health
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56 440 Malaysia).

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Supervisory committee

The supervisory committee will monitor the study process, from initiation to the end of the study. They will provide advice on the content of the study and its appropriateness with respect to the study aims. Monthly meetings are planned, and members of the supervisory committee will be asked for further input, if needed. Researchers and stakeholders will be a part of this supervisory committee.

Patient and public involvement

Participants were not directly involved in the study design. The FGD and IDI participants will only act as research participants. Meanwhile, the photovoice participants will conduct the photography session, give inputs in analysis, and participate in the exhibition. The researchers will conduct the final reporting and dissemination plan of this research.

DATA ANALYSIS

Data will be collected by the researcher and research assistants (RAs), who are proficient in the local language. The RAs will be trained by the research team and will be the observers, notetakers and translators. The RAs will assist in transcribing the data from the local language into English. We will use the qualitative software program ATLAS.ti Version 9 (ATLAS.ti Scientific Software Development GmbH), to assist with data handling, storing, and creating networks images, quotations, codes, themes, in a systematic way.

Thematic analysis

Thematic analysis by Braun and Clark will be used to generate codes and themes from the data.[57] Data familiarisation will be through re-reading the verbatim and re-viewing the

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3 466 photographs.[57] Familiarisation, is a time-consuming process which includes the phase of
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6 467 immersion, where researchers engage deeply with the data to find a richer meanings and
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8 468 generate patterns from the data.[57] In addition, this phase include critical engagement and
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10 469 note-making of thoughts related with the data.[57] Then, Initial codes will be generated
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12 470 systematically across the whole data set.[57] Themes will be identified within codes, and
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15 471 these themes will be named and defined.[57] Prior to the writeup, a review of the themes will
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17 472 be conducted.[57]

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21 22 474 **Rigor and data trustworthiness**

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24 475 Rigor is defined as the demonstration of integrity and competence within a study.[64] Data
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26 476 trustworthiness will be gained through feedback from participants (credibility, dependability),
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29 477 checks by participants and the research team (confirmability), and a thorough description of
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31 478 data collection and analysis (transferability).[61] Member-checking will be performed after all
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33 479 sessions of the chosen methods are completed.[61] For example, after an IDI session is
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36 480 completed, a summary will be given to participants to confirm or comment on the researcher's
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38 481 understanding throughout the session, and to maintain data accuracy. It will provide the
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40 482 opportunity to modify errors or wrong interpretations.[61] External coding will increase the
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42 483 validity of the data.[61] The coding process will be individually applied to the IDIs, FGDs, and
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45 484 photovoice data. The data will be triangulated to answer the research questions (RQs), as
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47 485 well as by generating new themes.[57]

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51 52 487 **Reflexivity of the researcher**

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54 488 Reflexivity and subjectivity are important characteristics of qualitative studies using thematic
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56 489 analyses.[57] The CBPR method encourages a self-reflective, engaged, and self-critical role
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58 490 among researchers.[27] The primary investigator (PI) in this study has 10 years of experience
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3 491 of working as a primary care medical practitioner in a rural district in Sabah, Malaysia. The
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6 492 PI will be the "facilitator" or "moderator" to guide the discussion between participants.[30]
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10 494 **Study outcome**

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12 495 Community participation in research is critical for developing information, education, and
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15 496 communication tools to produce and promote public health programmes.[27] The views and
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17 497 reflections of the community in the study are relevant for culturally sensitive and effective
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19 498 future *P. knowlesi* malaria-intervention programs. Furthermore, it could result in a more
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22 499 sustainable malaria interventions.[11] The outcome of this study will be used to inform the
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24 500 development of community-friendly and appropriate intervention tools. This approach is
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26 501 viewed as an essential component of ethical good practice in research.[27] It brings the
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29 502 communities' perspective and voices a way forward, through engagement in research, health
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31 503 equity and increasing the chances of success of an intervention.[11, 27] Intervention can be
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33 504 in the form of education, reflection, and discussion.[27]
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35 505 36 37 38 506 **Study status**

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40 507 The preliminary study was conducted from the 30th of December 2021 to the 28th of February
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42
43 508 2022. As part of the participatory approach, the gatekeepers (the healthcare workers and
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45 509 community leaders in the study sites), were met to introduce the study and discussed on the
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47 510 methodological feasibility and appropriateness of conducting the study during the COVID-19
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50 511 pandemic. In view of COVID-19 disease prevention, only fully vaccinated community
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52 512 members will be allowed to participate in the study and all participants needs to adhere to
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54 513 COVID -19 SOPs such as wearing masks and social distancing. The results of this
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57 514 preliminary study will be disseminated in future peer-reviewed manuscript.
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515 **Ethics and dissemination**

516 This study has been approved by the Medical Research and Ethics Committee, Ministry of
517 Health Malaysia (NMRR ID-21-01980-JEH), and the Research and Innovation Secretariat,
518 Faculty of Medicine, Universiti Kebangsaan Malaysia (FF-2021-462). All the participants will
519 provide consent prior to participation. Participants are allowed to withdraw at any point during
520 the study. The results will be disseminated in various academic (e.g. conferences, journals)
521 and non-academic (e.g. town hall meetings) platforms.

523 **DISCUSSION**

524 Efforts have been made to assess how CBPR can be an effective research methodology for
525 *P. knowlesi* malaria intervention. CBPR has possible important implications for the
526 sustainability and appropriateness of *P. knowlesi* malaria interventions. Many previous
527 programs have failed because of a lack of genuine community participation.[11] CBPR
528 provides insights from local people to improve the quality of research, ensure validity and
529 improve public health intervention.[27] The recognition of community perspectives on the
530 aetiology of illness, drivers of and barriers to preventive measures can provide a fresh
531 perspective on research issues, and helps to facilitate intervention tailored to local
532 conditions.[27] The engagement of communities has improved communication tools for the
533 promotion of effective and sustainable interventions, enhanced their relevance and feasibility,
534 and improved data utilisation by all stakeholders.[11, 27] The use of CBPR in health research
535 promises far-reaching changes in short- and long-term outcomes.[27] We hope to provide
536 empirical evidence to help develop future zoonotic malaria control programs. Community
537 engagement and feedback in our research will increase the reliability and validity of the study
538 through local knowledge and theory based on experiences. Changing the relationship
539 between researchers and those who participate in research involves a transformation of

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3 540 power and views of the issues that should promote a more flexible and reflexive process
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6 541 among researchers.[27] Participants will be empowered when their views and voices are
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8 542 heard.[54] Future studies and collaborations that combine CBPR methodology and
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10 543 emphasise on community participation will reinforce additional knowledge and appropriate
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13 544 behaviour changes.[27]

17 546 Study limitations

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20 547 It is possible that we may encounter a lack of trust among community members with the
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22 548 study, due to the limitation of time and space to engage with the whole community members
23
24 549 due to the current COVID-19 pandemic. We will attempt to minimise this by establishing trust
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26
27 550 through early communication and engagement with the head of the villages. Community
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29 551 members may be sceptical about participating in the study in case their opinions are
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31 552 considered invalid, thus a poor response rate in certain phases of this study may be
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34 553 encountered. A qualitative study is not a generalisable design but has the potential to develop
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36 554 an in-depth understanding of the community from a small number of participants.[30] Due to
37
38 555 differences in overall philosophy, assumptions, beliefs, decision-making, and values, conflicts
39
40 556 can arise between study members and different organisations.

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46
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4
5
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7
8 567 during their early years conducting malaria studies in Sarawak, Malaysia.
9

10 568

11 12 569 **Contributors**

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15 570 NAN was the principal investigator responsible for the design of the study and drafting the
16
17 571 manuscript. MRH was the coordinating investigator. RC, MSJ, RH, KA, and MRH contributed
18
19 572 equally to the content of the study protocol with important intellectual revisions. All authors
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22 573 read and approved the final protocol manuscript.
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28
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33 578 **Competing interests**

34
35 579 There are no conflicts of interest associated with this protocol.
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26 775 **Figure titles**

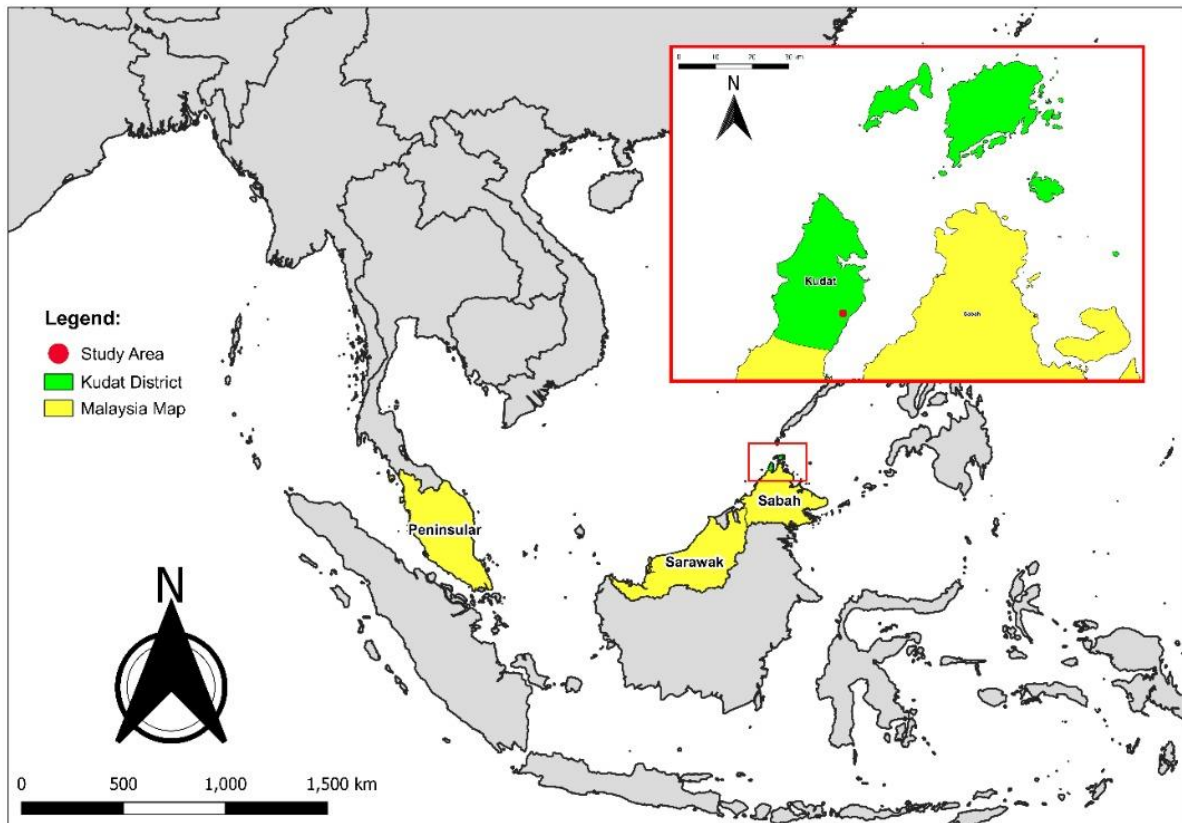
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28 776 **Figure 1. The study area**

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30 777 **Figure 2. The study flowchart**

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32 778 **Figure 3. The study framework**

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34 779 **Figure 4. The photovoice recruitment pamphlet in the Malay language**
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Figure 1. The study area



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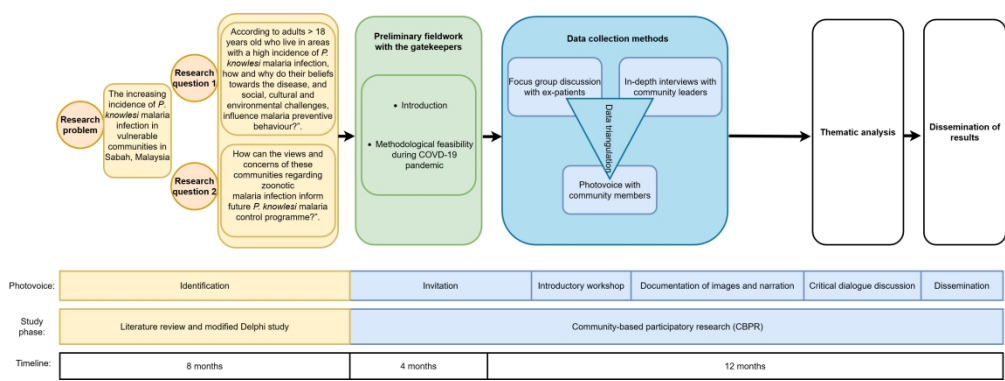
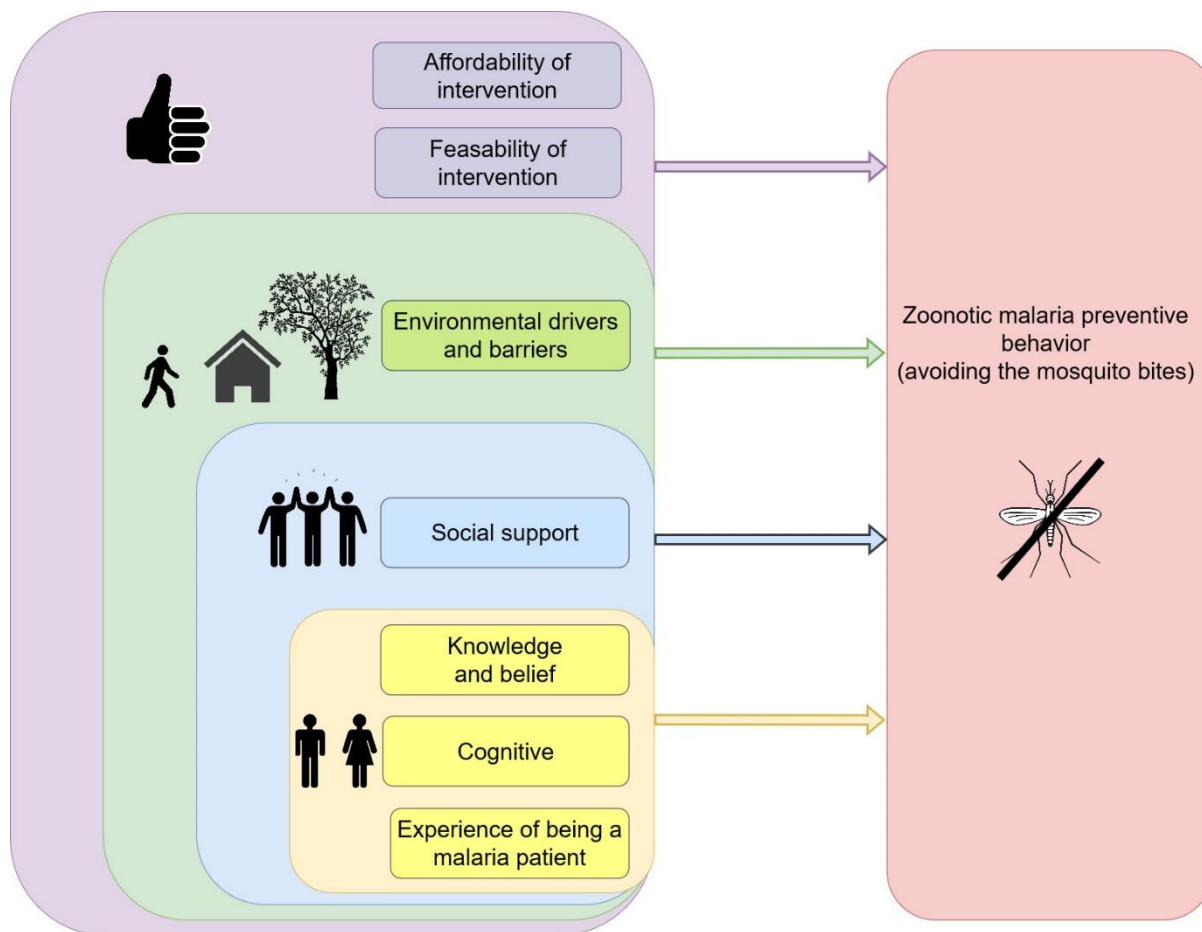


Figure 2. The study flowchart

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Figure 3. The study framework



Review only

Figure 4. The photovoice recruitment pamphlet in the Malay language

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DARI SUDUT MATA ANDA

MALARIA MONYET?

ADAKAH ANDA BERMINAT UNTUK BERKONGSI PANDANGAN?

- **BERUMUR >18 TAHUN**
- **PENDUDUK TETAP KAMPUNG DI KUDAT, SABAH**
- **MEMPUNYAI ALAT UNTUK MENGAMBIL GAMBAR (TELEFON, KAMERA, DLL)**
- **MEMPUNYAI TALIAN INTERNET**
- **MEMAHAMI DAN BERTUTUR DALAM BAHASA MELAYU / INGGERIS**
- **MEMBERI KERJASAMA DALAM SESI PERBINCANGAN**

LOKASI, TARIKH DAN MASA AKAN DIMAKLUMKAN.

JIKA BERMINAT, SILA HUBUNGI DR NURUL ATHIRAH (0199883361 ATAU DRATHIRAH85@GMAIL.COM)