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Navigating Informed Consent in Low-Literacy Ethnic Minority Populations: Insights from Northern Thailand

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Abstract

Securing genuine informed consent can be difficult, especially where literacy levels are low, yet it remains a crucial safeguard for individuals participating in global health studies. This paper examines the specific barriers to obtaining meaningful consent when recruiting research participants from mainly hill-tribe communities in northern Thailand. We examined the obstacles and possible ways forward to obtaining meaningful consent by conducting a qualitative investigation among a predominantly hill-tribe ethnic minority community in northern Thailand. This group is culturally distinct and has generally low literacy. Semi-structured interviews were conducted with 37 participants in a scrub typhus clinical study, along with their relatives, the research team, and additional key informants. A thematic analysis was then applied to the data.

Four interconnected themes emerged from our review regarding participants' ability to provide consent: varying levels of comprehension of the research, problems arising from reliance on informal interpreters, various influences on the decision to take part, and the degree of free will in giving consent. Proposed ways to reach more meaningful consent involved bringing in professional interpreters and building stronger links with the wider community involved in the research. People's ability to make informed choices about joining research projects requires active support. At the same time, details about the study must be shared with potential participants using language and methods they can clearly follow. Our findings showed that helping people gain a solid grasp of the research, including its possible advantages and drawbacks, goes far beyond simply improving literacy skills or providing translations. It also calls for close attention to the surrounding social and cultural context.

Keywords: Informed consent, Decision making, Literacy, Translators, Agency, Hill tribe

Introduction

Thailand has a sizable hill-tribe population, many of whom live in the rugged border highlands of the northern region. Every group maintains its distinct language, traditions, and worldview. In Chiang Rai province, the largest communities are the Akha, Lahu, and Hmong [1]. These hill tribe societies frequently experience social, political, and economic exclusion, which can heighten their health risks. For a long time, they were not officially recognized as Thai citizens, despite several generations having settled in the country after moving from nearby nations, including China, Myanmar, and Laos. As of 2021, more than 500,000 individuals were still officially listed as stateless, though the true number is probably

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higher [2]. Around 14% of the hill tribe residents in Chiangrai province lack Thai citizenship [1].

Lacking Thai citizenship means hill tribe members cannot receive free medical care, are barred from owning property, and face limits on travel [3-5]. Access to schooling is often reduced, and job options remain narrow, leading many to depend on casual daily work or farming [3-6]. Further challenges include living in remote areas, ongoing poverty, and difficulties communicating in Thai [3, 4, 6, 7]. Together, these barriers can seriously limit their ability to obtain healthcare services, contributing to poorer overall health and lower rates of preventive measures such as immunization [7, 8]. Involving hill tribe communities in clinical and public health research offers an important route to better identify their unique health problems, understand the obstacles to care, and design programs that better fit their actual circumstances.

A previous article by our team described how the routine hardships of hill-tribe life shape people's experiences when they join research projects, including how they weigh the visible and less obvious benefits and costs of taking part [6]. The current analysis focuses on the specific difficulties associated with the consent process, to support more respectful and effective inclusion of hill tribes in future health research.

Meaningful and legally sound consent stands as one of the core requirements of ethical research practice. It ensures that those considering participation receive sufficient clear information to understand what the study involves, including any potential risks or benefits [9, 10]. Even so, creating truly meaningful consent—responsive to people's specific needs and vulnerabilities while fully respecting their autonomy and personal agency (hereafter, 'meaningful consent')—remains a complex task [11-13]. Researchers disagree, for instance, on exactly how much and what kind of information should be shared, and on how much understanding is needed before a decision can be considered properly informed and voluntary [11, 14]. In addition, the decision-making process varies widely and is shaped by social, cultural, and political realities, including the availability of alternative healthcare routes. These broader conditions can weaken the truly voluntary nature of participation decisions [15, 16].

This paper examines the specific barriers to obtaining meaningful consent when recruiting research participants from mainly hill-tribe communities in northern Thailand. This topic emerged as a major theme during our international project, REACH: Resilience, Empowerment and Advocacy in Women's and Children's Health. The project worked to clarify how ideas of vulnerability and personal agency apply in research ethics. We also suggest practical steps that could strengthen consent procedures for other disadvantaged populations.

Materials and Methods

Study setting and methods

Chiang Rai is a largely rural province in northern Thailand. It lies adjacent to Myanmar on its northern side and to Laos to the east, forming the famous Golden Triangle, where the borders of all three nations meet. By 2020, the area was home to 1.3 million residents, of whom around 20% were from hill-tribe ethnic minority backgrounds [17, 18]. Among Thai provinces, Chiang Rai is among the economically disadvantaged, with typical household earnings reaching only 354 British Pounds per month, compared with a countrywide average of 620 British Pounds [19]. Farming serves as the chief means of earning a living.

The Chiangrai Clinical Research Unit functions as a compact outpost linked to the Mahidol Oxford Tropical Medicine Research Unit (MORU), headquartered in Bangkok, an organization launched in 1979. Located in the province's main city, this unit began operations in 2015 to tackle pressing local health concerns through scientific inquiry. Its work covers topics such as scrub typhus, various fever conditions, and field-based investigations in global health bioethics.

Linked scrub typhus studies

Participants for the qualitative component were selected from two separate clinical projects focused on scrub typhus. This illness often goes unnoticed but is a primary trigger of fevers without a clear cause throughout Thailand [20-22]. Caused by bacteria, it spreads when people are bitten by infected mites that thrive in rural areas, thereby increasing the risk for anyone living or working in such places [23, 24]. Overviews of those clinical projects are presented in **Table 1** [6]. Among the pair under review, the first is a randomized controlled trial (RCT) designed to determine the best treatment approach for scrub typhus. The second involves an observational study examining how the body's immune system responds to scrub typhus in both younger and older individuals.

Table 1. Linked scrub typhus study details. From: The challenges and potential solutions of achieving meaningful consent amongst research participants in northern Thailand: a qualitative study

Study details	**Scrub typhus antibiotic resistance trial (comparing doxycycline and azithromycin in regions with reported resistance)**	**Eschar investigations to enhance diagnostics, early immune response understanding, and strain characterization for vaccine development in scrub typhus**
Study design	Randomized controlled trial (RCT)	Observational
Aims	Identify the most effective treatment for scrub typhus by comparing three oral antibiotic regimens	Enhance understanding of early immune responses to scrub typhus and explore potential early diagnostic markers
Study population	Patients aged ≥ 15 years hospitalized with non-severe scrub typhus	• Patients aged ≥ 7 years AND • Presenting to hospital with scrub typhus OR • Controls with skin injuries or undergoing minor surgery, who either had scrub typhus previously or reside in endemic areas
Study processes	• Random assignment to 1 of 3 treatment groups • Collection of demographic and clinical data • Blood and urine samples at enrolment • Daily clinical assessments during hospitalization • Additional 6 or 12 blood samples during the following week • Follow-up at 2 and 8 weeks (clinical data, blood and urine samples)	**Patients:** • Demographic and clinical data • Eschar swabs, scrapings, or biopsies • Lymph node aspirates in a subgroup • Blood and urine samples at enrolment • Follow-up at 2 weeks (clinical data, blood and urine samples) **Controls:** • Demographic and clinical data • Blood and urine samples at enrolment • Skin biopsies
Study benefits	• Receives treatment for scrub typhus (though most would be entitled to standard free care) • Compensation for time and reimbursement for actual travel costs during enrolment and follow-up visits • Contributes to future improvements in scrub typhus treatment	• No direct therapeutic benefit • Compensation for time and reimbursement for actual travel costs during enrolment and follow-up visits • Contributes to enhanced understanding of disease severity and diagnostics for scrub typhus
ClinicalTrials.gov identifier	NCT03083197	NCT02915861

1. Adapted from Greer *et al.* [6] vulnerability and agency in research participants' daily lives and the research encounter: A qualitative case study of participants taking part in scrub typhus research in northern Thailand.

Procedures

The investigation followed a combined ethics and case study framework. This case revolved around people engaged or previously engaged in one of the related clinical scrub typhus efforts. Input was also gathered from relatives of these individuals, members of the research staff, representatives of ethics review boards, and notable figures in the local community to fully define the case boundaries.

Semi-structured interviews ran from March 2018 to June 2019. REACH interviewees were selected across three categories through a combination of deliberate, purposive sampling and snowball sampling. The first group included women and children who joined the research (central to the REACH initiative), as well as members of their households drawn from the two clinical projects. Group two brought together investigators, medical staff, and ethics board members connected to the clinical activities. Group three featured important local voices, including health personnel, regional investigators, and community leaders. In all, 37 people joined the effort, while six declined the invitation, chiefly because of limited availability.

Interviews were led by NK, a Thai research nurse, and RCG, a British physician specializing in research and residing locally in Chiang Rai. As women, both interviewers had solid familiarity with the surrounding environment and had completed specialized training in qualitative research methods. Before the formal sessions, NK typically connected with most participants to go over what taking part in REACH would entail. A number of those placed in Group 2 hold positions within MORU, matching the employer of both NK and RCG.

Sessions occurred at locations chosen for ease of access for the interviewees—whether at home, the job site, or nearby medical centers—and lasted an average of 80 minutes. Conversations happened in either everyday or northern Thai, or in English. Whenever participants lacked comfort with these languages, skilled interpreters from hill-tribe communities (specifically Akha and Lahu) stepped in. These interpreters brought prior experience and received targeted briefings on the project itself, along with careful walkthroughs of the planned questions. Recordings captured every discussion, which were then fully transcribed and translated into English as needed. Customized sets of interview questions [6] were developed and initially tested for each participant category.

Regarding the material covered here, individuals from Group 1 described their firsthand experiences with the clinical projects, including recruitment steps, the consent process, and the extent of their understanding of the overall research. Those in Groups 2 and 3 shared thoughts on the moral issues associated with research activities in this location, recounted their observations of consent procedures, and offered views on the depth of participants' comprehension. Following each conversation, NK and RCG reviewed the key points together, occasionally involving additional colleagues. The collection of interviews continued until no major new insights emerged [6].

Analysis

Examination of the material relied on thematic analysis grounded in a realist view of knowledge [25, 26]. Patterns emerged inductively through initial open coding, followed by repeated collective review meetings among the team. From this emerged a structured coding system that was applied and refined in successive rounds. Using NVivo Pro 11, both NK and RCG processed every written transcript. Differences in how codes were assigned prompted joint discussion until full alignment occurred. Broader input on the codes and resulting themes came from the rest of the research group as well. Presentation of outcomes follows a straightforward descriptive storytelling style [6].

Results and Discussion

In total, semi-structured interviews involved 37 respondents, with five additional follow-up conversations conducted, one of which was held jointly with two people **(Table 2)**. Nearly all individuals in Group 1 had hill-tribe backgrounds (16/19, 84%), predominantly Akha or Lahu. The bulk held Thai citizenship (16/19, 84%), while two held authorization to reside in the country, and one lacked any formal legal status. Roughly one in three in Group 1 relied on an interpreter during the interview, and half reported never having attended school [6]. The ages of the interviewed children ranged from 8 to 17 years.

Analysis brought forward four linked themes that highlight difficulties in reaching meaningful consent: (1) wide differences in how much participants understood the research, (2) shortcomings tied to reliance on casual interpreters, (3) the pathways people follow when choosing to enter research, and (4) elements that shape whether consent feels truly voluntary. Options for improvement were also considered. Supporting quotations appear where helpful, are tagged by respondent category and identifier, and note the clinical study format (RCT or observational, when it matters). Any interpreter involvement in the REACH sessions is mentioned.

Table 2. Breakdown of REACH respondents. From: The challenges and potential solutions of achieving meaningful consent amongst research participants in northern Thailand: a qualitative study

Respondents (number)	Interviews conducted (number)	Additional interviews (number)
Group 1: Research participants and their family members from linked scrub typhus studies (19)	Research participants (14), family members (5)	Follow-up interviews (4: 3 with research participants, 1 with a family member)
Group 2: Research staff from linked scrub typhus studies (9)	Research nurses (3), senior research physicians (2), hospital nurses (2), ethics committee members (2)	Dyadic interview with 2 research nurses (1)
Group 3: Key community informants (9)	Primary care nurses (3, including 1 who is also a research nurse), research nurse (1), doctors and researchers (2), village chief (1), director of a non-profit organization (1), informal translator and former village health volunteer (1)	_

Total	37	–

1. Reprinted from Greer *et al*. [6] vulnerability and agency in research participants' daily lives and the research encounter: A qualitative case study of participants taking part in scrub typhus research in northern Thailand.

Varying degrees of research understanding

Group 1 participants showed a wide range of comprehension about the study and what their involvement entailed. Most realized they had enrolled in a research project and recognized basic procedures such as blood sampling and scheduled follow-up visits. Fewer understood that their eligibility stemmed from having scrub typhus. This observation was reinforced during the paired interview with the two research nurses, who explained:

'How well someone grasps the study really hinges on their personal background and education. Some individuals may not have attended school, so their insight remains quite basic. They might know only the immediate tasks required of them without fully appreciating the deeper goals of the project or the reasons behind each step.' (Research nurse 29, dyadic interview)

'Yet in my experience with most people, they tend to follow the practical side of joining — things like having blood drawn, taking prescribed medication, or tracking body temperature. They usually understand those steps clearly. What they often miss or receive less detail about is background knowledge on the illness itself, its causes, and related information.' (Research nurse 01, dyadic interview).

Many other aspects of the research remained unknown to participants during our conversations, including how randomization worked and the project's precise objectives. Still, several mentioned that the work aimed to enhance treatments, and some believed it would eventually help others: 'They plan to share the findings publicly, develop better medicines, and find ways to eliminate scrub typhus so this kind of insect no longer harms us.' (Scrub typhus observational study participant 10).

'The team carries out this work to support other patients. That way, when someone gets sick later, doctors will already know effective ways to treat them.' (Scrub typhus RCT participant 03).

On multiple occasions, even after receiving explanations, Group 1 individuals indicated that their grasp of the study stayed quite limited: 'She knows she has this sickness, which is why she could take part. The staff went over everything with her, but she still couldn't follow it properly. She just couldn't get it.' (Scrub typhus RCT participant 16, speaking through an interpreter).

Interestingly, several people admitted they joined the study anyway despite feeling they lacked a full understanding or had only partial insight: 'Even though the explanation was given, she said she didn't really get it. Nevertheless, she agreed to participate.' (Scrub typhus RCT participant 13, speaking through an interpreter).

Factors impacting understanding

Several elements tied to both participants and researchers shaped how well people understood the research. Across all respondent categories, those with formal schooling, strong Thai language skills, and prior research experience tended to absorb study information more readily. Every group highlighted the additional difficulties faced by hill-tribe members or migrants who spoke little Thai and relied heavily on interpreters.

'When it comes to explaining things clearly, educated patients catch on quickly. But with people who have lower levels of education, no matter how carefully we describe it, they often only pick up that the doctor invited them to join some study. They receive basic details, stop asking questions, sign the form, and move on. They rarely develop a genuine sense of what the research actually involves.' (Healthcare worker 27).

'For patients who struggle with language and communication, we can never be completely confident that the message gets through when it passes via an interpreter. We don't know if their level of understanding matches what we would achieve by speaking directly in the same language.' (Research nurse 29).

Participants' prior views and encounters with research also played a role. For many, this was their initial contact with any research activity and, frequently, their first time staying in a hospital. Most (except those in the control arm of the observational study) were actively ill with scrub typhus at the time of recruitment in the hospital setting. One person recalled feeling drowsy, which clouded her memory of events. Earlier reports have noted that the strain of illness — whether affecting the individual or their child — can impair a person's capacity to absorb information and provide truly meaningful consent [27, 28].

Additional influences stemmed from the researchers themselves: how clearly they communicated, the vocabulary they chose, how much information they presented at once, and the supporting materials provided. Although Group 1 members recalled that staff explained procedures gradually, some still felt overloaded and could only retain the core ideas:

Interviewer: What exactly did the nurse tell you?

12: She covered everything… but there was so much that I can't recall any more of it now [laughs].' (Mother of a scrub typhus RCT participant 12).

Instead of the formal Thai term for research, the nurses often spoke of a "project" or "study" to make the idea easier to follow. However, this approach risked blurring the line between research activities and ordinary medical treatment. Neither the Akha nor the Lahu languages has a direct equivalent for the word "research," which added another layer of difficulty in conveying and grasping the concept. Furthermore, the RCT examining the best treatment for scrub typhus overlapped considerably with the standard clinical care these patients received for the same condition.

Limitations of using informal translators

Trial participants who cannot speak Thai require interpreters' assistance. In practice, hill tribe members or others with limited Thai proficiency usually arrived at the hospital accompanied by a family member who served as an ad-hoc translator, since professional interpreters were not regularly available. This arrangement brought both advantages and drawbacks. On the positive side, translators helped participants learn more about their condition, the research itself, and enabled them to pose questions to the medical team. They could also offer emotional support and practical advice.

She mentioned that everything sounded unclear while the staff spoke in Thai. But as soon as the translator stepped in and explained, things became much clearer, and she could finally picture what was happening (Mother of a scrub typhus observational study participant 19, speaking through an interpreter).

Nevertheless, the accuracy and completeness of the translations differed widely. Informal translators receive no specialized preparation and must rely solely on their own knowledge to render complicated medical and research terms. One sister-in-law described translating only what she herself could follow:

'She could pick up the main ideas — that treatment would start soon through this team, using certain medicines in a particular way. But there were quite a few terms she only partly understood or missed entirely, which left her feeling confused.' (Sister-in-law of a scrub typhus RCT participant 14, speaking through an interpreter).

Key pieces of information sometimes disappeared during translation. For instance, the sister-in-law who interpreted knew the research was optional, yet the Group 1 participant she assisted remained unaware of this. Other translators described the opportunity as "good" and encouraged joining, or instructed people to press their thumbprint on the consent form without clarifying its significance:

'The niece who translated didn't go into any details. She just said it was a positive step and that she should take part. That was all, so the participant agreed.' (Scrub typhus RCT participant 13, speaking through an interpreter).

'She only realized she needed to give a thumbprint. She had no idea what the project involved. Her neighbor, acting as translator, told her to do the thumbprint, so she followed along without further explanation.' (Scrub typhus RCT participant 17, speaking through an interpreter).

Respondents from groups 2 and 3 expressed concern that details could be unintentionally distorted in translation and noted the heavy reliance on these interpreters. Overall, family members appeared more reliable than other casual translators, even if they were not always the most capable at conveying technical content. Relying on interpreters also made it harder for researchers to verify whether potential participants truly understood the information:

'How can we confirm that everything important was actually communicated? It's difficult when we don't speak their language.' (Local doctor and researcher, 26).

In the end, the influence of informal translators determined how well information was conveyed, how deeply it was understood, and whether individuals could make a genuinely free choice about participation — all critical components of achieving meaningful consent.

Decision making to join research: from active decisions to no explicit decisions made

Group 1 participants approached the decision to participate in the scrub typhus research in very different ways. Some made a deliberate, conscious decision; others allowed the research team to proceed with procedures; and a few appeared to make no clear decision at all. Nevertheless, every participant signed the consent form or provided a thumbprint.

Several group 1 respondents reported making a firm, intentional choice to join the study. Their reasons varied: wanting to discover the cause of their symptoms, seeking medical care, or hoping the work would eventually help others. The belief that participation would not harm them also played a key role in their reasoning.

'I considered the matter carefully on several occasions and concluded that this project was worthwhile. It causes no harm and aims to support people, so I chose to take part.' (Scrub typhus RCT participant 11).

A research nurse similarly recalled overhearing family discussions at the bedside in which patients weighed the advantages and disadvantages of joining:

'Family members would talk among themselves near the bed, asking things like "Should we join? Is it a good idea?" … "There doesn't seem to be any downside, and it could help others too." … "It's fine to participate."' (Research nurse 01, dyadic interview).

For other participants, the decision was far less definite. They described allowing the researchers to collect blood samples or perform other study activities, rather than actively choosing to enroll. Some said they gave little thought to the matter:

'She didn't really consider anything. She assumed the team had come to draw blood and treat her illness, so she allowed them to take the samples. She felt she would agree to whatever might help her recover from this sickness.

Interviewer: Who actually decided at that moment?

Interpreter: She says no one really decided. They said they wanted to take blood samples, and she let them proceed.' (Scrub typhus RCT participant 17, speaking through an interpreter).

Some researchers and ethics committee members worried that individuals could end up participating simply by not objecting.

For certain group 1 respondents — all from hill-tribe communities and dependent on interpreters — it was unclear whether they had personally decided to take part. Several described being instructed by their informal translator to press their thumbprint on the consent form with minimal explanation of its significance. Elsewhere in the interviews, they mentioned being informed about the study and its procedures, yet it remained unclear how much they truly understood at the time they "consented."

'Her sister-in-law, who was translating, didn't explain anything. She told her to provide the thumbprint, so she went ahead and did it.' (Scrub typhus RCT participant 14, speaking through an interpreter).

Even so, none of these participants expressed any regret about having joined the study. One said she would encourage others to participate, while others felt glad that they had recovered from scrub typhus.

Factors influencing voluntariness of consent

Beyond the social pressure from family members and informal translators already mentioned, several other factors shaped participants' decision to join the research. These included the expected benefits of the study — especially access to medical care — as well as the burdens it placed on participants. Cultural factors, such as respect for and confidence in healthcare professionals, also played a role, along with the research's effects on the immediate family and the broader community. Researchers and ethics committee members recognized these influences, and for some, the central ethical issue was ensuring that participation remained truly voluntary.

'What concerns me most is whether researchers give participants enough time and a real opportunity to ask questions before they agree to join. Many people view hospitals as helpful institutions, so when a doctor asks them to participate, they feel they should not refuse — they believe they ought to assist. This sense of obligation, or "kreng-jai," can become the strongest reason for joining without carefully reviewing all the details.' (Local ethics committee member, doctor and researcher, 32).

Although all Thai citizens and most group 1 respondents were eligible for free healthcare regardless of whether they joined a study, the prospect of receiving treatment remained a key perceived benefit in both the RCT and the observational study. This appeared to be a significant factor in their willingness to participate [6]. One individual, for example, joined primarily to learn the cause of her symptoms and to obtain suitable treatment. This motivation likely reflects wider structural difficulties in accessing healthcare within this population. The close link between research involvement and receiving proper care for their illness may also point to therapeutic misconception, especially since treatment and research activities overlapped considerably, particularly in the RCT. Some potential participants also worried that declining to join might negatively affect the care they received:

'For Thai people, refusing is often hard. They come seeking hospital services and are then invited to take part in a project. Most lack the confidence to say no. They fear that turning down the invitation could influence how they are treated afterward. Whether they truly want to join or not, they usually end up participating anyway.' (Local ethics committee member, doctor, and researcher, 08).

A small number of researchers worried that offering financial compensation might undermine voluntariness if the amount was substantial, effectively pressuring people — especially those living in poverty — into joining:

'If the compensation is quite large, it starts to feel unethical — almost like purchasing patients for research. That is why the amount must be kept modest. Otherwise, it can sway the parents' or guardians' thinking and push them toward entering the study.' (Local doctor and researcher 26).

In contrast, most group 1 respondents regarded the compensation as a welcome extra but stated that it had not affected their choice to participate in the research.

In addition to the benefits, the perception that the research would have no negative impacts on participants influenced some decision-making.

Beyond the expected advantages, the belief that taking part would cause no harm also shaped the choices of several participants:

'When the research nurse invited me to join this kind of study and asked if I was comfortable with it, I replied "Yes." After all, it wouldn't cause me any problems, and it actually offered clear benefits.' (Scrub typhus RCT participant 21).

Cultural elements also played a significant part in how people decided whether to participate. In Thailand, both the general population and hill tribe communities tend to show great respect for healthcare professionals and often feel a strong sense of duty to assist them. In the past, many hill-tribe groups had limited access to the healthcare that Thai citizens receive, so medical missionaries sometimes helped fill that gap. These early medical workers are still remembered and respected by the communities they once helped. Healthcare staff, ethics committee members, and researchers worried that the Thai cultural value of 'kreng-jai' — which involves being considerate, showing respect, deferring to others, and avoiding anything that might cause discomfort or hurt feelings [29] — could lead patients to agree to research mainly to please or show respect to the researchers rather than because they genuinely wanted to take part.

'People feel kreng-jai toward the doctors and nurses. The staff need their cooperation, and the patients feel they lose nothing and face no harm, so they think, "Why not help them?" When doctors ask for assistance, patients often say "aow-aow" [okay, sure] out of kreng-jai rather than because they fully understand the study.' (Healthcare worker 27).

All respondent groups agreed that trust in doctors and healthcare workers, combined with the high esteem in which they are held, strongly influenced decisions. Some Group 1 participants described following the doctor's recommendation to join:

'The doctor explained the project and suggested I take part, so I went ahead and signed the form.' (Mother of scrub typhus RCT participant 12).

Although most respondents believed that most participants could make a voluntary choice, one doctor and ethics committee member expressed concern that when healthcare workers or researchers approached patients directly, it could unintentionally create pressure to agree. This risk seemed especially high when understanding was limited, and decisions relied heavily on trust or personal relationships with the medical team, as a research nurse noted. At the same time, some argued that basing a decision on trust and established relationships can be a valid approach.

'Some people may not fully understand the details, yet they agree immediately because they know us well, have a comfortable relationship with the team, and trust the staff. They give consent right away.' (Research nurse 23).

Suggestions for achieving more meaningful consent

Increasing research understanding

Both researchers and Group 1 participants emphasized the importance of understanding the research before making a decision. They agreed that the main responsibility lies with the research team to ensure potential participants have sufficient comprehension to make an informed choice. Overall, Group 1 respondents offered few ideas for improving their own research experience, but several specifically requested the use of a professional interpreter. They felt this would ensure that all important details were clearly conveyed and would strengthen their grasp of the study and the true meaning of the consent process.

She mentioned she would prefer to have a proper translator because she cannot speak Thai. It seemed as though she had not understood what the doctor was explaining (Scrub typhus RCT participant 14, speaking through an interpreter).

Another group 1 participant noted that she had been feeling drowsy during her hospital stay, so having someone present to assist and interpret would have been very helpful. A village leader emphasized the value of using a translator from the same community who understands the local context and has good intentions. A woman who had served as an informal translator added that, beyond simply converting the words, she could also chat with participants and help them feel more relaxed.

Other recommendations for better understanding included taking sufficient time, offering straightforward explanations, and communicating in a friendly manner:

‘What the team has done up to now is already positive. The main request is that everyone speaks kindly to one another, discusses things together, and keeps talking until everything is clearly understood.’ (Scrub typhus RCT participant 03).

Information should be delivered in small, manageable portions, one step at a time — particularly when working through a translator:

‘It might help to break everything down into small blocks, like stacking toy blocks one by one. Keep it simple. Explain what will be used first, then what will happen next, and so on. Go through it from the very beginning to the final step so participants can see the complete picture of the research from start to finish.’ (Healthcare worker 15).

Community engagement was also proposed to strengthen understanding. A village chief recommended holding local gatherings where people could share ideas and learn more, while a researcher suggested inviting former participants to talk about their experiences.

‘We could arrange a training session or seminar for exchanging views. Setting up a proper stage might make it even more effective [laughs].’ (Village chief 24).

Including participants’ support networks in the process was another common suggestion, acknowledging that decisions are often shaped by both the individual and the collective family or community. One Group 1 respondent proposed that researchers involve a family member who could understand the information and help her discuss it. A research nurse noted that recruitment typically occurs within the hospital, away from participants’ usual community and support systems. Although individuals technically have the right to decide for themselves, she felt it would be better to involve the wider community. On a broader scale, raising general education levels, improving Thai language skills, and increasing public awareness of health and research topics could also help enhance individual understanding.

Ensuring voluntary decision making

The key recommendations for helping participants decide freely whether to take part were to clearly state that the decision was entirely theirs and to ensure they fully understood the study. Most people felt that having witnesses present offered important protection for participants. Other ideas included asking patients to return on a different day if they wished to participate and promoting the studies via posters instead of speaking to patients directly:

If we put up posters to invite them, they can decide whether to join. But if we [researchers/healthcare workers] approach them personally… It’s like… they are ‘kreng-jai’ [considerate], they don’t dare to refuse.’ (Local ethics committee member, doctor, and researcher 08).

To prevent payments from exerting undue influence on potential participants, this issue was typically raised near the end of the consent discussion. One respondent from group 1 also pointed out the importance of paying family members for their time when they helped with follow-up appointments.

Obtaining truly meaningful and valid consent is a core ethical requirement for any research involving people, but it remains difficult to achieve in practice [11-13]. Ethics guidelines list the details that should be shared and understood by those considering joining, yet the significance of each piece of information varies from person to person [10, 14, 27, 30, 31].

In northern Thailand, where our work focused mainly on hill-tribe communities, we discovered that participants often received so much information they could not recall most of it. Their understanding of the research varied widely. Several people in Group 1 demonstrated very limited comprehension and could not clearly explain their decision to join; instead, they followed the translator’s instructions and placed their thumbprints on the consent form. This inconsistent understanding did not appear to depend on whether the study was an RCT or an observational one. Studies across many locations have repeatedly shown that research participants often have only a partial understanding of what they are joining; this problem occurs worldwide and is not unique to settings with fewer resources [12, 13, 27, 32]. Moreover, people need different amounts of information and different depths of understanding before they can reach a decision. What counts as enough understanding for one person may fall short for another. Crucially, knowing facts about the research does not always mean true understanding, and understanding itself is not always the main factor in people's choices [33]. Millum and Bromwich argue that a complete understanding of every aspect of the research—including all possible risks, benefits, and experiences—is not achievable. What matters most is that participants grasp what consenting actually involves, know they are free to say no, and understand the core commitment they are making—the hardest element to secure [34].

Informal translators played a valuable though imperfect role in supporting participants who did not speak Thai. They helped these individuals learn more about their health condition and gave them the chance to join the study. This assistance is especially vital in regions with many minority languages where informal translation is routine. Both formal and informal translators can serve as advocates, but informal ones often view their job as not only translating but also guiding and supporting people [35, 36]. Informal translators have said that feeling rushed leads them to shorten explanations, leave out details, or delay translating certain points [35, 36]. To boost their clients' comprehension, they may add, remove, or change wording and stress or soften particular messages [36].

In some cases, we observed that the translation of study details was insufficient, making it even harder to ensure participants had a clear understanding of the research. Since achieving a solid understanding is already difficult when everyone speaks the same language, it is no surprise that extra difficulties arise when using a translator, and that informal translators tend to introduce more mistakes than trained ones [37, 38]. As in other contexts, understanding was also hindered by the large volume of information provided, lack of familiarity with the illness or with research in general, and the reality that many local languages have no exact word for "research" [11, 12].

Even with these obstacles to comprehension, it is worth noting that the people we interviewed described how trial participants still exercised some degree of personal choice in deciding to join, even when that choice was limited [39]. The level of active decision-making varied—from making a deliberate choice, to having no clear decision at all, to simply going along with what others suggested. Choices were rarely made alone; they were shaped by social, cultural, and economic realities. Family members, translators, and healthcare staff all influenced decisions to varying degrees. Trust in others and cultural norms, such as 'kreng-jai', sometimes encouraged participation [12, 40, 41]. The idea of 'kreng-jai' resembles the common pressure to be polite and avoid turning down requests from outsiders, a pattern observed in places like Kenya and India [11]. This dynamic is not inherently negative. Bull and Lindegger explain that other people's influence on research participation can range from independent voluntariness (where the person decides but is still affected by others), through cooperative decision-making, all the way to situations where the decision is essentially made by someone else, resembling proxy consent [16]. Similarly, Ngure and colleagues stress the value of acknowledging that decisions to join research are often social in nature, especially in Kenya, and propose a more relational approach to supporting participants' autonomy [42]. Thailand's predominantly collectivist culture, which emphasizes the group over the individual, values contributing to others' well-being. This collective outlook can sometimes conflict with personal autonomy. For example, someone might join a study to assist healthcare workers or to benefit the community in the future. The real difficulty lies in ensuring that every participant—particularly those who depend on others—has the chance to make an independent or cooperative decision about taking part.

Several people invited to participate in this qualitative study declined, most citing a lack of time. However, one woman initially said yes to an interview, but as the details were explained on the day, it became obvious she felt uneasy and did not really want to proceed. Even after we reassured her that the decision was completely hers, that she had no obligation, and that she should not feel 'kreng-jai' toward us, she still did not refuse outright. Instead, she suggested doing it on another day. We provided our contact information and invited her to call if she changed her mind. We have not heard from her since. Comparable examples of "silent refusals," where it is hard to tell whether someone truly wants to join or continue, have been noted in other studies [43].

Even small payments or access to healthcare services can have a powerful effect on people's decisions to participate in research. This pattern aligns with findings from many other studies conducted in low- and middle-income countries, where receiving medical care is often a primary motivation for participating in a study [12, 15, 27, 44]. When research takes place in settings marked by poverty and limited resources, these broader structural conditions must be carefully taken into account during study design, so that any benefits offered are fair yet do not feel coercive. Simply offering a choice is not enough on its own. Researchers must also make sure the options presented to participants are genuinely meaningful; an ‘empty choice’ does not meet ethical standards [15]. Kingori explains that individuals’ decisions to participate in research are frequently shaped by structural and situational realities, such as having few or no other options for obtaining healthcare. In such cases, even though a formal choice exists, it can become an ‘empty choice’ or feel like no real choice at all [15].

Our study provides a broader and more complete view of the consent process by drawing on perspectives from a wide range of respondents involved in hospital-based research in northern Thailand. Including interpreters enabled us to understand the experiences of hill tribe members who do not speak Thai, an important group that is often underrepresented in this region. Nevertheless, even with training for our interpreters, their involvement in the interviews still created limitations. This made it more difficult to fully explore how well participants understood the clinical studies. The absence of a direct word for ‘research’ in the Akha and Lahu languages added further complexity. There was also a time gap between when Group 1 participants gave consent for the clinical study and when we conducted our interviews. This delay was partly intended to allow time for recovery from illness. Still, it may have reduced their ability to accurately remember details. It could have led us to underestimate how much they truly understood about the consent process and the research itself.

We believe that many of the difficulties identified in this study will feel familiar to researchers working in other environments, particularly those related to communicating research clearly and helping participants reach a sufficient level of understanding. Potential solutions and lessons learned should be shared worldwide and then adapted to local contexts. Researchers should recognize that some people will agree to join studies even when their understanding of the research is limited and they still have doubts, while others may not even realize they have enrolled in a research project. Research institutions should collaborate closely with participants and local communities to improve understanding of what consent really means and what it will involve for them. Community engagement initiatives can help raise overall awareness of research within the community, rather than leaving the full responsibility on individual participants and researchers at the time of recruitment. Examples of such efforts include partnering with community advisory boards or community representatives [45, 46]. Additional local work is underway to develop materials with the community for use in the informed consent process and to provide clearer explanations of common research terms. Thorough planning is essential when deciding on the language, presentation style, and amount of information provided to every participant. In response to the translation difficulties we encountered, we created a network of trained formal interpreters during the data collection period to assist patients throughout the entire informed consent process. These interpreters received training to ensure that all important information was accurately conveyed, supporting patients in making informed decisions. When translation is necessary, back-translation should be employed to confirm that the main messages are communicated accurately and clearly. Researchers should also receive training on how to effectively work with interpreters when needed. Ongoing evaluation will be important to determine whether these steps are successfully improving participants’ understanding of research and making the consent process more meaningful overall.

When designing research studies and obtaining informed consent, it is essential to consider local decision-making practices and the social and cultural influences that can shape them. The power imbalances that exist when healthcare workers or researchers—especially those from different cultural or economic backgrounds—invite patients to join a study must be carefully considered. In the end, addressing broader health inequalities and power differences is necessary to support genuine voluntariness in research participation. More research is needed on practical ways to help participants make more active, deliberate decisions about whether to participate in studies.

Conclusion

Obtaining truly meaningful consent is difficult, yet it remains a fundamental ethical duty for all researchers. Details about the research must be presented to potential participants in language and formats they can clearly understand so that they can make well-supported decisions. The choice to join a research study is rarely based only on how well someone understands the research itself. Instead, it is also shaped by the perceived benefits and burdens of the study, as well as important social and cultural considerations.

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