

## **Informed Consent Form in Local Language: Challenges and Issues in a Multilingual Study Design among Migrants**

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### **Abstract**

In this paper, I discuss the challenges and issues of translating informed consent form in the local language in multilingual study design among culturally diverse migrants' populations. From ethical and legal perspectives informed consent is an important requirement for conducting research where human participants are involved. The concept of informed consent was an integral part of the principles of the Nuremberg Code, the Declaration of Helsinki and the Belmont Report (Code, 1949, Puri et al., 2009, and Cassell, 2000). While applying application for ethical clearance the principal investigator needs to translate the informed consent form from English to local Language as part of the ethical guidelines. Nevertheless, in a multilingual setting among migrants, it is difficult to follow the ethical guidelines to translate into the local language. To overcome this hurdle, it is desirable to follow the common language speaking among the migrants. I follow common speaking language and simple English for the informed consent form while getting informed consent from the Northeast migrant workers as most of them use to communicate in English. It is helpful to establish trust and voluntary participation in the research.

**Keywords:** Informed Consent, Local Language, Migrants, Multilingual, Ethical, Legal, Challenges, Common communicating Language, Trust, Voluntary Participation.

### **1.1 Introduction**

This paper stems from ethical challenges and issues of Informed Consent (IC) form translation into local language as part of the ethical guidelines while applying to an Institutional Ethics Review Board (IERB). In our 21<sup>st</sup> century there has been an increase in the awareness of ethical considerations and therefore certain guidelines are set by the national and international ethical boards to be followed by the principal investigator so as to respect the dignity of the respondents, trust, maintaining confidentiality, and to allow voluntary participation in the investigation as a subject or respondent (Ritchie et al., 2013). The Ethics Review Committees or the IERB or Independent Ethics Committees in many countries serve as a competent body to evaluate, review and make a decision on the scientific and ethical merits of the research

proposals (Israel and Hay, 2006 and Kim, 2012). The IERB gives ethical guidelines to translate the informed consent form into the local languages. Ethical principles and guidelines are important for the protection of human subjects in research (Flory and Emanuel, 2004).

Both from ethical and legal perspectives it is important to translate the IC form into the local languages. This is a big dilemma between the ethical guidelines and the empirical problems when the respondents are from different multilingual social groups. The pertinent question is which local language we should follow. Then shall we follow either the official languages or the scheduled languages? Or, the guidelines set by the IERB? As a principal investigator, I had faced the challenges of translating the IC form into the local language as directed by the IERB as I do not have competence in speaking Hindi nor translation. My respondents had also faced the same challenges as many of them don't understand Hindi. I might follow the instructions of the IERB guidelines and translate it into Hindi by hiring a professional Hindi language expert, but it would not help much in my research as it would only serve as ethical clearance formality without addressing the empirical reality of the challenges and issues of translating into the local language.

## **1.2. Methodological Challenges and Issues working among Multilingual Migrants**

As discussed above, I had explained to the IERB committees about the methodological empirical issues of translation of local language since I was working among multilingual migrants social groups and finally my application was approved for the ethical clearance to conduct the research and take the informed consent in English as I have also mentioned that most of my respondents use to communicate in English as they belong to different ethnic groups having different languages and dialects. Cox and Dauby (2014) case study among foreign-language patients in a highly multilingual hospital emergency department had also faced the same challenges and issues of obtaining informed consent. They experimented with audio-recorded explanations of the consent form in various languages (Cox and Dauby, 2014). India is a multilingual country and therefore there is no language for India. The social reality in a country like India is that there are still many communities who do speak neither the official languages nor the scheduled languages. According to the 1971 census, there are about 220 languages spoken in the North Eastern Region of India.<sup>1</sup> Conducting research among the Northeasterners<sup>2</sup> with the specific guidelines of translating the informed consent form into the local language is a great challenge.

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<sup>1</sup> Resource Centre for Indian Language Technology Solutions, Indian Institute of Technology, Guwahati. Available at [http://www.iitg.ac.in/rcilts/phasel/n\\_e.html](http://www.iitg.ac.in/rcilts/phasel/n_e.html) [Accessed on 29 December 2018].

<sup>2</sup>People coming from the North Eastern Region of India are collectively known as Northeasterners.

The option of hiring professional language expert to translate it into the local language involves a plethora of ethical challenges. First, the interpreter may translate it on behalf of the principal investigator where she/he does not have the competence of the language. Nevertheless, in doing so, it does not help to solve the language barrier between the principal investigator and the respondents. In this regard, Pernice (1994) has identified six methodological difficulties while conducting research among refugees and immigrants. In this paper, I will discuss two of them as they are very relevant with the kind of argument I am making. The first challenge is linguistic problems and the second one is conceptual problems with translation into the local language in a multilingual setting. In fact, the most important ethical in practice while conducting research is to get the “trust” of the respondent for her/his voluntary participation in the research/project. Let us discuss this from the empirical methodological challenges and issues that I had faced during my fieldwork.

### **1.3. The Challenges and Issues I had faced in the Field**

I did a pilot study among the Northeast migrant workers before I had submitted my IERB application. The broader objective of my research is to understand the reasons of out-migration from the borders and periphery of Northeast India to Delhi and the positive and negative consequences of migration and their impacts on health and well-being of the northeast migrant workers living in Delhi in the last 1-10 years and their resilience model of coping mechanisms. I was conducting fieldwork in 2016 in one of the sites where people from Northeast India largely take accommodation in South West Delhi. In this site inside the narrow lane in the evening, there are at least 3-4 distinct faces of Northeasterners among the crowds. There are Northeast Shops on every side of the narrow lane building where many varieties of local vegetables, dried fish, meat, black rice, lentils, dried vegetables, tin fish, fresh bamboo shoots, tin bamboo shoot etc., are sold here. It is quite interesting that most of the Northeasterners food cultures include vegetables, lentils, cereals, and other medicinal food plants in a contrast to the popular belief of the culture of eating meat only.

My respondents are from the eight states of North Eastern Region of India, which comprises of Arunachal Pradesh, Assam, Manipur, Meghalaya, Mizoram, Nagaland, Sikkim, and Tripura. From each state, there are at least three to four different ethnic groups who also speak different languages and dialects in the sample of my study. There are eight states and since there are 3-4 different languages and dialects I have to translate into all these languages and dialects in order to follow the ethical guidelines of the informed consent form. I need at least 32 professional language experts in order to translate to the local languages which are big challenges and issues. Therefore, the first challenge and issue is the linguistic barrier and the second is a conceptual translation. For example, when I was conducting the pilot study, I used to ask my respondents what they would translate “research” in their own language and dialect.

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Most of the poor resource communities were difficult to translate it. One of the respondents from Manipur said “research” means “*hiram amada thijin humjinbagi thabak*”<sup>3</sup>, in short, “*thijin humjinba*” and one of the communities from the same state but different in ethnic community translated “research” as “*hawlchil or khuolchil*.”<sup>4</sup> And, another community from the same state translated “research” as “*phu gutmei*” or “*phu sinhmei*.”<sup>5</sup> While another community from one of the North Eastern States of India translated “research” as “*gobexona*” or “*gobehona*.”<sup>6</sup> Therefore, while translating the conceptual meaning of the “research”, I found more than one word in different communities. One of the non-Northeast scholars translated “research” in Hindi as “*shodh*.” The point is that translating to multilingual local languages would bring time-consuming, more expenditures, and many challenges and issues. Chima (2013) empirical study succinctly explains the challenges experienced by doctors obtaining informed consent in the complex multicultural societies which includes multilingualism.

Obtaining IC from a diverse multilingual social environment that does not share a common language or dialect, was a challenge for a researcher like me who works among the migrants in the metropolitan city. In this case, mediation by a professional interpreter is not helpful as it may give impact while building trust and budgetary issue (Nijhawan et al., 2013). Trust is the first threshold to enter into the voluntary participation of the respondents to get the required information that is sought by the researcher. It is very obvious that signing a document or any paper without knowing its content and meaning would definitely have doubts and fear. These challenges and issues were overcome as most of the Northeasterners use to communicate in English when they meet with other ethnic social groups.

#### 1.4. Conclusion

Therefore, unless research is conducted among a single community, it would be very helpful to use English as a medium to get informed consent, especially from Northeast people if the research is conducted among the different ethnic groups by a Northeast researcher or non-Northeast researcher. Those who do research on their own community should translate to their local language as it will better serve to build trust and consent for voluntary participation in the research.

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<sup>3</sup>One who is researching in a subject in *Meeteilon*, the Language of the Meiteis in Manipur.

<sup>4</sup> Kukilon, the dialect of the Kukis in Manipur and translated by a Postdoctoral scholar on 28.12.2018 at JNU.

<sup>5</sup> Rongmeilon, the dialect of the Rongmeis in Manipur, translated by a senior of a social activist.

<sup>6</sup> Assamese Language. *Gobexona* and *gobehona* were translated by two different respondents having different spellings but same meaning.

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