

# Conducting research ‘with’ not only ‘about’ refugees

Saleh Aljadeeah

## Why are refugees often not involved in research that directly pertains to them?

In this blog post, I will answer this question by reflecting on my experience with refugee involvement in research, particularly in the healthcare field.

Refugees are a heterogeneous group in terms of country of origin, reasons for flight, socio-economic status, and educational background. Before, during and after their flight, refugees are exposed to diverse risk factors for mental illness, infectious diseases, and chronic diseases. It is important for governments of high-income countries to be equipped to respond to the healthcare needs of this population, including with reliable data. Such data is critical for planning needs-based healthcare services for refugee populations. However, refugees are not included in [national health monitoring in Germany](#) or in many other European countries.

Therefore, researchers who are interested in conducting health research studies among refugees need to collect primary data.

Despite the growing emphasis on community involvement, there remains a lack of refugee involvement in research about their health, including defining research questions, designing the methods, and analysing research outcomes. This situation has resulted in the underrepresentation of refugees’ voices in the research that impacts their lives. In this blog post, I reflect on my experience with refugee involvement in research from two angles: as a researcher who conducted research with refugees about their access to and use of medicines, and as a participant in studies focusing on refugee populations.

## Why do we need to involve refugees in research?

First, involving refugees in research projects can help to overcome challenges such as language barriers and cultural issues to avoid including questions that seem offensive, discriminatory, or irrelevant to the target population. Researchers from the Robert Koch Institute, the leading national health institute in Germany, [reported some problems based on their experience during data collection](#). While participants of two nationalities considered questions regarding religion as offensive, other participants of different nationalities considered some sociodemographic questions irrelevant to the health topic of this

research study. This example explains why some migrants and refugees may be hesitant to participate in health research studies. It also emphasizes the need for active and meaningful involvement of migrants and refugees at all stages of research studies targeting their communities to avoid such problems that discourage them from taking part in the research. Some refugees I interviewed mentioned that they were asked to participate in surveys where they could not understand the purpose of some questions, or how some research projects would help to improve their health or living situation.

***Involving refugees in designing survey questionnaires enhances the possibility of creating questions that make sense to the participants and addressing issues that interest participants.***

Researchers should not cut their contact with refugees after data collection. Some refugees I interviewed complained that the outcomes of the surveys in which they took part were not shared with them later. The researchers 'disappeared' after collecting the data. If researchers believe that the outcomes of their studies are beneficial for refugees, they should share these outcomes with them. This behaviour of some researchers has been also [reported by Naohiko Omata](#). Beyond sharing results, refugees can help interpret and explain research outcomes at the stage of data analysis and interpretation, especially in quantitative research.

Moreover, involving refugees in health research can enhance the sustainability of these projects as refugee populations can implement or benefit from the study outcomes beyond the duration of the projects. This involvement can also help disseminate the outcomes and information resulting from the research to reach a wider public. Involving refugees in research shows refugees that their experiences are appreciated and their voices are heard by researchers. In addition,

involvement in research can encourage refugees to be more vocal in their advocacy for the rights of refugees.

## Why are refugees often not involved in research?



Some researchers focus on their expertise in their research topic and are not prepared or open to considering the opinions or perspectives of refugees. The common misconception that refugees have lower levels of education contributes to this issue. The group of refugees that I consulted as part of my research was diverse in terms of educational attainment, and some provided me with valuable advice that I had not found

elsewhere. For example, as I shared my questionnaire with them, one of the members of this group commented on the first part of my questionnaire, which included questions about the participants' demographics: 'These questions remind me of the questions the migration authorities asked me during the interview for my asylum application'. This participant suggested changing some terms and the order of these questions so that the questionnaire did not seem so much like the asylum interview. This simple yet relevant advice gives an example of a reason behind the common hesitancy of refugees to take part in survey studies and it emphasizes the need to involve refugees in research.

Some researchers are too busy to take part in data collection and hire others to collect data from target populations. These data collection teams are usually provided with training only about asking questions and recording participants' answers. As a result, those who collect the data often cannot adjust the survey strategy or questionnaire based on feedback from participants, which creates a gap between researchers

and refugees while silencing the refugees' voices in the research. For example, I was invited to participate in a survey about the integration of refugees into the university system in Germany. Some questions in this survey were unclear to me. I also had questions about the suggested multiple-choice answers to some close-ended questions and their relevance to the research topic. The data collection team members could not provide an answer to my questions, they stated that they were just 'master students' who were hired 'only' to collect the data. I was advised to contact the Principal Investigator and discuss my questions with that person instead. This experience is an example of a common disconnect between researchers and refugees, as researchers determine the questions that refugees should answer, then third-party data collectors interact directly with refugees to collect the data and bring the data back to the researchers for analysis. This one-directional flow of information leaves no place for refugees' input or opinions outside the frame that researchers have already set. In order to address this disparity, researchers interested in doing research with

refugees should conduct pilot testing of their data collection tools and dedicate part of their time to going to the field and interacting with members of the refugee community to address their concerns or questions related to the questions they are asked to answer.

Having direct contact with refugees during data collection is necessary. However, this contact should be initiated at earlier stages of research projects. At the data collection stage, researchers have already defined their research questions and developed their data collection tools or instruments. It may be too late then to consider new perspectives on the fundamental direction of the research project. Researchers should, instead, try to engage with refugees at earlier stages of planning and implementing their research. There are other factors that contribute to the lack of refugee involvement in health research, including a lack of training for researchers to involve refugee populations in their research. Moreover, refugees are not used to being asked about their opinion regarding research projects.

## Recommendations

### 1. Involving a Refugee Advisory Group in Designing the Research

Without involving refugees in their research, researchers dismiss important perspectives that could help improve research planning and implementation and overcome challenges related to different stages of their research process. I want to emphasise that the involvement of refugees in research should be a cornerstone of each research project that targets refugees in order to capture the diversity of refugee perspectives and experiences. I encourage researchers who are interested in refugee research but who have no previous professional experience working with refugees to engage with refugees and learn about their experiences before starting their research that targets this population. Research institutions that provide courses on research methods should provide researchers with the needed training about community involvement in health research and address any particular issues that need to be considered while involving refugees in research.

Researchers should contact members of the target refugee population at an early stage of planning for their research projects and ask them to be part of a group that the researchers will consult throughout the planning and implementation of the research project. This group should be diverse in terms of nationality, age, sex, and level of education to cover different perspectives of the target population. Researchers should discuss their research questions with this group and ask them to suggest any additional aspects or issues which should be addressed in the research. Researchers should also discuss the methods they want to apply in their research, including the instruments used for data collection, the translation of these instruments, the sampling methods, the recruitment strategies, and the data analysis methods.

Moreover, research funding agencies should include in their funding guidelines a requirement that researchers involve their target population while developing their research proposals. In funding applications, researchers should include a plan for involving their target population in their

proposed research projects. Institutional review boards should invite members of refugee communities to discuss the potential effects of the proposed research projects on the target communities.

## 2. Compensating Refugee Participants

Another concern is the compensation of refugees. Researchers should compensate the members of this group for their research involvement. The [UK National Institute for Health Research](#) considers offering to pay 'public contributors' for their involvement in research a 'good practice'. Why should refugees be excluded from this 'good practice'? Providing material compensation to participants in research has been [considered a controversial issue in forced migration studies](#), but Omata suggests that it might be a way to ensure some level of reciprocity and benefit to participants, even if the research findings do not end up changing policy. This issue needs to be reconsidered and discussed further. Researchers [should at least](#)



[reimburse all reasonable expenses associated with the involvement of refugees in research](#), such as the costs of travelling to meeting sites.

### 3. Analysing the Data & Sharing Results

Finally, when analysing data, researchers should return to the Refugee Advisory Group that helped design the study. Researchers should discuss the results of their studies with this group and ask them for an explanation of these results. Researchers should also discuss with this group the dissemination strategies of their results to improve the possibility that these results or outcomes of research would be considered in the discussion about refugees' health.

Academic journals that share research can also play a role in promoting refugee involvement. For example, several journals of the British Medical Journal portfolio require authors of research articles to add a patient and public involvement statement in their submitted manuscripts. Journals that

focus on research in forced migration issues should encourage community involvement in research by requesting that authors provide community involvement statements in their submitted manuscripts.

#### **Saleh Aljadeeah**

Postdoctoral researcher, Institute of Tropical Medicine, Antwerp, Belgium.  
Twitter: [@SalehAljadeeah](#)

#### **Acknowledgment**

I thank Professor Sarah Phillips (University of Sydney) for her suggestions and comments on earlier drafts of this blog.