

Lessons from pandemic research with refugee communities

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Key points

- Refugees and other CALD people are under-represented in Western research, however, the refugee experience may impact various practical aspects of the research process
- Researchers and institutions can improve the research process for refugee people by being flexible, adaptive and culturally aware
- Our research conducted with people from refugee backgrounds during the coronavirus 2019 (COVID-19) pandemic demonstrates that trust, and an established relationship with the community are vital
- Including participant groups such as refugees in the planning and conduct of research will drive more ethical and practical research

Abstract

Culturally and linguistically diverse (CALD) people are subject to many inequities worldwide, and research is no exception. We report lessons learnt as researchers conducting a qualitative study during the coronavirus disease 2019 (COVID-19) pandemic involving participants of refugee backgrounds. We found that despite the best intentions of the research team, a variety of factors in methodology and data collection presented unexpected barriers for our studied population. We share our reflections to assist others in their research endeavours. Researchers and institutions have a moral obligation to provide research practices that are both suitable and beneficial to the community. Collaborating with community members in the research process allows researchers to create ethically sound, practical studies with maximum utility.

Introduction

In 2021, researchers from a NSW Government Multicultural Health Service (MHS) and Public Health Unit (PHU) in regional Australia undertook qualitative research to explore how new and emerging refugee communities learnt and shared information about coronavirus disease 2019 (COVID-19) health messages. Participants were primarily community members from four ethnically diverse refugee communities in two regional towns. Despite attempts to overcome anticipated research challenges, we encountered several noteworthy dilemmas, which we describe here with the aim of assisting others in their research endeavours.

Four MHS staff conducted small group (up to five participants) or individual interviews with 30 people of refugee background (18 general community members and 12 influential community members) and a further seven people of other culturally and linguistically diverse (CALD) backgrounds across the two regional towns. Interviewers included a refugee health doctor, a multicultural health liaison officer and two refugee health nurses. The nurses were well-known to the refugee participants. Three of the

four staff self-identified as being of CALD background. Participants were interviewed in small groups or individually, with face-to-face interpreters as necessary. Apart from three interviews, all were conducted in person.

Reports of our findings can be found in the published literature.¹⁻³ Our reflections outline which research processes worked well and those which offered lessons for future improvements.

What was done well

Ethics process

The ethics process was relatively smooth, taking approximately 4 months for approval as a low-risk study with the local research ethics committee; approval number: 2020/ETH02955.

Interpreters

We enlisted interpreter services early, producing flyers and the Participant Information Statement (PIS) in the four main respective languages of the study population: Arabic, Dari, Kurdish-Kurmanji and Swahili. The statement was simplified and presented in both written and video format to cater for a range of literacy abilities. We were fortunate that two video interpreters were also influential members of the studied communities, affording familiarity and trust to prospective participants.⁴ Given the heterogeneity of individuals within ethnic groups, we were mindful of enlisting interpreters who spoke dialects familiar to the participants who enrolled. This was crucial, especially for consent purposes.

Recruitment

As we were aware that many people of refugee background value trusted relationships, most participants were invited for interviews directly by their locally known refugee health nurse. We enlisted some influential community members known to us via networking circles to assist with snowball recruitment by personally inviting other participants. Notably, some influential community members who were not personally known to the research team were either uncontactable or unwilling to engage in the research project. Having a pre-existing relationship with community members and influential community members benefited participation in our research.

Transport

Many of our refugee community members do not drive, have access to private cars, or have the autonomy, confidence or ability to navigate public transport. Although a taxi voucher may sound like a simple solution to travel problems, it requires a command of the English language and trust in an unknown driver, factors that may not be acceptable for recently arrived immigrants, particularly those from a refugee background. Knowing

this, we arranged private transport for many participants to the local health centre to participate in research interviews, either by a known case worker or a research team member. We found that by personally collecting the participants and taking them home after interviews, we were able to meet the research recruitment goals while also developing rapport with study participants.

Location

Teleconferencing was offered for interviews with influential bilingual community members. We elected to undertake face-to-face interviews with community members to avoid any barriers related to digital literacy. According to the COVID-19 Public Health Orders in place at the time of the interview⁵, some interviews were permitted at participants' homes, while others were conducted in a conference room at the local health district campus. The specific room and building were selected for their desirable features: free parking, IT equipment, toilet amenities, a kitchenette and sufficient space to accommodate social distancing requirements. Most importantly, it was adjacent to a familiar landmark – a dental clinic where the participants had received prior health services. Overall, the researchers felt that interviews conducted in participants' homes were superior, as they eliminated the need for participant transport. Home visits benefited recruitment as other family or friends who were also in attendance were willing to consent and participate in the study.

Waiving signatures

We observed that some formalities of research appeared to increase participant hesitancy and uncertainty. It was clear that some participants appeared uneasy and suspicious when asked to provide a signature for the consent form. To compound the issue, a regulation from our research funding body required participant signatures to receive all gratitude gift vouchers. Given the complexities of trust and identity risks concerning those with a history of trauma and displacement, it is not surprising that our participants might have been wary. To reduce the discomfort, researchers sometimes opted to accept verbal consent over written signatures, as pre-empted in our Ethics submission, recorded by one researcher and overseen by a second witness.

Trust is a must

We found that refugee community participants were best engaged when the lead interviewer was their local refugee health nurse, with whom the community had a strong and longstanding relationship. Rapport with other researchers was established by employing an extended informal chatting time prior to interviews, taking extra time during the consent procedure and assisting in transport and refreshments. We felt that establishing rapport was

essential for participants to feel comfortable with the interview process.

Considerations for improvement

More flexibility

We struggled to recruit male community members for the study, as we found men were often working at the time of scheduled interviews. Some prospective participants invited us to interview them at non-conventional places and times when they were available, for example, on a Sunday morning at the church building or a weekday evening at their home. In the future, we would advocate for more flexibility regarding staffing hours and apply for alternative locations to be considered, noting that occupational health and safety standards would need to be met.

Participant Information Statement (PIS)

We found that community members with low education still could not fully understand the PIS, even in the simplified video format, thereby nullifying informed consent. We re-explained the statement's key points, doing so through active dialogue with each participant, using the on-site interpreter. This process, although extremely time-consuming, was vital to ensure informed consent and was helpful for rapport building. (See simplified english transcript of PIS, Supplementary File, available from: figshare.com/articles/journal_contribution/TRANSCRIPT_community_members_pdf/21405255)

Telecommunication

Due to the rapid introduction of COVID-19 lockdown restrictions, final interviews unexpectedly needed to be done by three-way telephone call (involving the researcher, participant and interpreter). Despite the apparent simplicity of using a telephone, we found technical issues with clarity and speech volume over the telephone, making interpretation difficult. As we were unable to read non-verbal cues, at times, there was confusion with turn-taking between the participant, researcher, and interpreter. Rapport was also challenging to establish over the telephone. We felt face-to-face interviews were superior to telephone and would avoid the latter in future.

Discussion

The production of quality refugee research has the potential to advance human rights.^{6,7} People who have experienced forced migration may encounter specific barriers to participating in research studies, such as power imbalances and concerns about safety, uncovering authentic fears around consent and identity exposure.⁸ As we found, practical challenges may complicate the

research process: issues related to literacy, economics, transport and time constraints.⁹ Gatekeepers of research have a moral responsibility to identify challenges and tailor research methodology to maximise opportunities for refugees to engage with research if they choose to do so.¹⁰

The cost of interpreters for non-English speaking participants may discourage some researchers, limiting recruitment to trials and thus resulting in a lack of refugee representation in the literature.¹¹ Professional interpreters were vital for the execution of our study at various points. Besides effective language communication, interpreters provide cultural insights and contribute to social equity.¹² Healthcare interpreters are bound by ethical codes, including confidentiality, and are trained to meet institutional standards.¹² Failing to use professionally trained interpreters puts participants, researchers, and the wider community at risk of harm from miscommunication.¹²

Numerous researchers support using participatory action research when engaging with refugee communities.^{6,13} The principles of such research are relevant to the research process and the ethical framework in which it is conducted.¹³ Although our study was not conducted as participatory action research, we consulted influential community members for preliminary scoping and the recruitment process. In retrospect, consulting influential community members during the ethics process may have provided additional insights into more suitable methodology processes to consider.

As with our experience, other researchers have also found that traditional informed consent processes involving signed consent forms may not work in practice for refugee participants and that asking them to provide signatures may not be culturally acceptable.^{6,13} Alternatives include voice recording verbal consent or using a witness to record consent on the participant's behalf.¹³ Based on reciprocity, participatory research has the advantage that participants interact with the research process at various points, thus gathering a more longitudinal understanding of the study and enhancing informed consent.¹³

We were fortunate to have existing long-term professional relationships with most participants based on trust and respect. Establishing relationships may take years, but they continue past the research phase.¹³ Continual consultation with the community is necessary for research action and strengthens ties for future collaborative work.¹³

By respectfully partnering with refugee communities, researchers can learn how to apply and produce quality research in a truly ethical and practical manner that benefits the community. We urge all gatekeepers of research to be mindful of the broader context presented by refugee participants and encourage flexible, dynamic tailoring of research processes.

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Peer review and provenance

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Competing interests

None declared.

Author contributions

SH was the major contributor to the conception, writing, editing and revisions of the manuscript. NG contributed to writing, editing and modifications. Both authors were extensively involved with the research discussed in this manuscript.

References

1. Healey SJR, Ghafournia N, Massey PD, et al. Ezidi voices: The communication of COVID-19 information amongst a refugee community in rural Australia- a qualitative study. *Int J Equity Health*. 2022;21(10).
2. Healey SJR, Ghafournia N, Massey PD, et al. Factors contributing to the sharing of COVID-19 health information amongst refugee communities in a regional area of Australia: a qualitative study. *BMC Public Health*. 2022;22:1434.
3. Healey SJR, Ghafournia N, Bolsewicz K, Andrich K, Massey PD. The role of leadership among a Congolese community in Australia in response to the COVID-19 pandemic: a narrative study. *Western Pac Surveill Response*. 2022;13(2):1–6.
4. Wild A, Kunstler B, Goodwin D, Onyala S, Zhang L, Kufi M, et al. Communicating COVID-19 health information to culturally and linguistically diverse communities: insights from a participatory research collaboration. *Public Health Res Pract*. 2021;31(1):e3112105.
5. Public Health (COVID-19 Additional Restrictions for Delta Outbreak) Amendment (No 18) Order 2021 under the Public Health Act 2010 NSW Government, 5 August 2021. [cited 2022 Oct 17]. Available from: [https://legislation.nsw.gov.au/file/Public%20Health%20\(COVID-19%20Additional%20Restrictions%20for%20Delta%20Outbreak\)%20Amendment%20\(No%2018\)%20Order%202021.pdf](https://legislation.nsw.gov.au/file/Public%20Health%20(COVID-19%20Additional%20Restrictions%20for%20Delta%20Outbreak)%20Amendment%20(No%2018)%20Order%202021.pdf)
6. Halilovich H. Ethical approaches in research with refugees and asylum seekers using participatory action research. In: Block K, Riggs E, Haslam N, editors, *Values and vulnerabilities: the ethics of research with refugees and asylum seekers QLD*: Australian Academic Press; 2013. p. 127–50.
7. Block K, Riggs E, Haslam N. Ethics in research with refugees and asylum seekers: processes, power and politics. In: Block K, Riggs E, Haslam N, editors. *Values and vulnerabilities: The ethics of research with refugees and asylum seekers*. QLD; Australian Academic Press; 2013. p. 3–19.
8. Müller-Funk L. Research with refugees in fragile political contexts: how ethical reflections impact methodological choices. *J Refug Stud*. 2021;34(2):2308–32.
9. Hughson J, Woodward-Kron R, Parker A, Hajek J, Bresin A, Knoch U, et al. A review of approaches to improve participation of culturally and linguistically diverse populations in clinical trials. *Trials*. 2016;17:263.
10. Refugee Studies Centre. Ethical guidelines for good research practice. *Refugee Survey Quarterly*. 2007;26(3):162–72.
11. Howerton MW, Gibbons MC, Baffi CR, Gary TL, Lai GY, Bolen S, et al. Provider roles in the recruitment of underrepresented populations to cancer clinical trials. *Cancer*. 2007;109(3):465–76.
12. NSW Health. Policy directive: interpreters- standard procedures for working with health care interpreters. Sydney: NSW Government; 2017 [cited 2022 Mar 18]. Available from: www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2017_044.pdf
13. Hugman H, Bartolomei L, Pittaway E. Human agency and the meaning of informed consent: reflections on research with refugees. *J Refug Stud* 2011. 24(4):655–71.

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