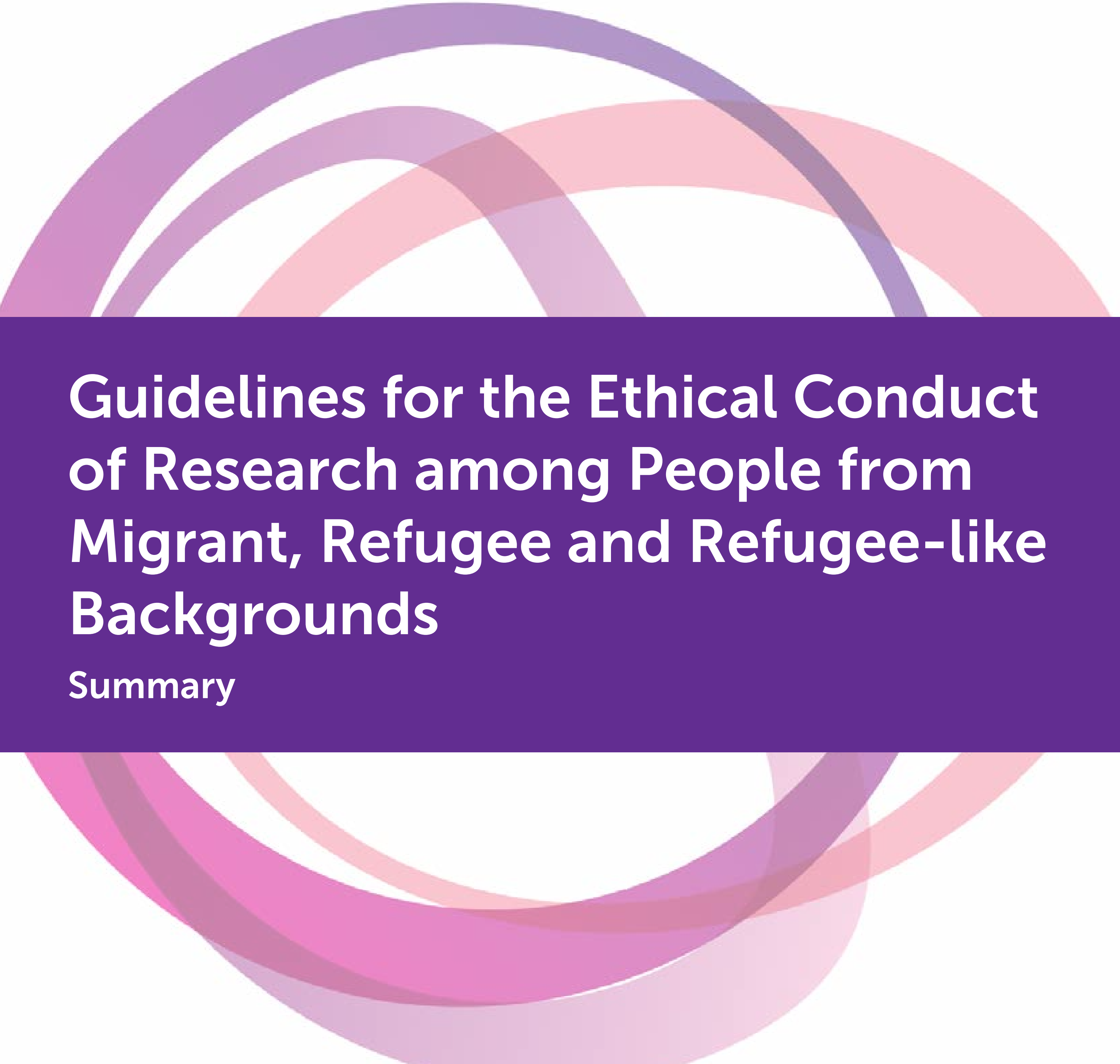

Guidelines for the Ethical Conduct of Research among People from Migrant, Refugee and Refugee-like Backgrounds

Summary

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Acknowledgments

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The Migrant and Refugee Health Partnership brings together health professionals and the community to address systemic barriers to health access for migrant and refugee communities. We also seek to strengthen health-promoting assets in communities, recognising that improvements in the health and health system literacy have a direct positive impact on community health and wellbeing.

The Social Policy Group is a national, non-government, not-for-profit body with specialist expertise in social policy and program design with a focus on population diversity, social and community cohesion, gender equality, community participation and inclusion, systems' responsiveness, and community outreach and engagement.

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Executive Summary

This paper outlines the case for guidelines for the ethical conduct of research among migrants, refugees and asylum seekers. This is a heterogeneous group of people who have in common the experience of displacement from their birth or former country of residence. Some of this group have experienced forced displacement and many may use a language other than English as their preferred language. Australia has the largest proportionate migrant population in the OECD, and has been a long-standing humanitarian resettlement site, with over 7.5 million migrants, including 900 000 refugees, having settled in Australia since the end of the second world war. Australia ranks eighth for linguistic diversity in global comparisons, but is also the third most monolingual country in the world. This means that four out of five Australians speak only English fluently, with the remaining fifth speaking one of over 250 languages.

Despite Australia's long experience as a migrant country and refugee resettlement country, there is evidence that they are frequently excluded from clinical trials, are under-engaged in research co-design and that research priorities do not consider the needs of their communities, particularly in translational research.

In common with all OECD countries with large migrant populations, Australia has no national guidelines on ethical conduct in this field.

The NHMRC National Statement has been effectively applied to develop guidelines on ethical conduct among Aboriginal and Torres Strait Islander people. This has had a transformative impact on the practices of human research ethics committees and research in Aboriginal and Torres Strait Islander communities. No such guidelines exist for Australia's migrant and refugee population.

Recommendations

1. That the NHMRC support the co-production of ethical guidelines for migrant and refugee populations drawing on the National Statement.
2. That the NHMRC undertake to consider endorsement of such guidelines after they have been co-produced with communities and disseminated among stakeholders for review.

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Introduction

Globally, the systematic violation of human rights and the heightened complexity of geopolitical affairs, economic forces and climate induced circumstances are driving unprecedented numbers of people to seek international protection.[1] Consequently, the interest and volume of research concerning people from migrant, refugee and refugee-like[i] backgrounds has increased in Australia and internationally.[2,3] The global COVID-19 pandemic has unmasked Australian health inequalities for migrants and refugees, limited access to frequently changing health information, reduced opportunities for communities to participate in immunisation, clinical research and wider public health measures and increased morbidity and deaths.[4]

Research with migrant and refugee communities is important to improve access to health services, understand lived experiences of health, identify baseline health needs and gaps in service delivery and public health interventions, and to develop evidence-based policies and interventions for improved equity, health outcomes and social care.[5] It is imperative that there remain concurrent measures in place to protect the wellbeing of research participants from migrant and refugee backgrounds and ensure research is culturally responsive, trauma informed and accessible.[6]

The overarching National Statement on Ethical Conduct in Human Research (2018)[7] guides all human research in Australia. Currently there is an absence of formal targeted National Health and Medical Research Council (NHMRC) equivalent guidelines which include specific cultural, ethnolinguistic, trauma and socioeconomic considerations for migrant and refugee-like populations. Some organisations and communities have developed guidelines and recommendations to provide principles and strategies for researchers, organisations involved in migrant and refugee-related research and communities themselves to participate and gain access to dissemination of results.[8] However, these are designed for local use or specific types of research rather than for human ethics research committees, and are not endorsed by professional Colleges or national research bodies such as the NHMRC.

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[i] Hereafter referred to as migrant and refugee backgrounds

Many researchers have highlighted concerns regarding the processes of research involving those from migrant and refugee backgrounds[9,10] and their exclusion from participation and publication in medical literature.[11,12] The populations are heterogeneous, representing various and intersecting backgrounds across culture, religion, race, language, gender and trauma, among others, complicated by broader cross-cutting issues of, human rights, and social justice. The communities also have wildly varying socioeconomic and visa status, which may impact health, legal and community connections and visibility,[13] Limited English proficiency is frequently reported amongst many subgroups.[5,6,11]

Additionally, there are specific groups such as asylum-seekers and those on temporary visas who may live for prolonged times in uncertainty over their futures and often lack the same societal rights (e.g. access to case workers, to the right to work, to tertiary education or social security payments) or access to health and social services in contrast to the rights of humanitarian entrants or migrants.

These contextual factors impact the lives and wellbeing of those from migrant and refugee backgrounds and highlight why research and routine data collection across social, economic and health frameworks is important in order to identify how our systems can be improved for more equitable outcomes. However, these same factors can clearly impact individual's trust of authority and government, fear of speaking out if living with uncertain visa conditions, concerns about privacy and increase the risk of exacerbation of trauma in not undertaken with a trauma informed approach.[14]

In summary, research among migrants and refugees frequently deals with the intersecting issues of power and consent, lack of adequate language resources, confidentiality and trust, and consequent risks of harm to participants and communities they belong to.[5,15] These considerations highlight the need for a national set of guidelines for the conduct of ethical research among migrants and refugees.

What Currently Exists in Australia

A number of documents have been developed addressing some elements of this puzzle, but without formal citing of the National Statement.

Developers	Title	Focus
Kaldor Centre for Refugee Law; Asia Pacific Network of Refugees; Asia Pacific Refugee Network; University of Essex; Refugee Council of Australia; University of Auckland;	Guidelines for co-produced research with refugees and other people with lived experience of displacement, Feb 2023 [Discussion draft]	Refugees in Asia and the Pacific; does not have a health focus
Australian Association of Gerontology, the Federation of Ethnic Communities' Councils of Australia (FECCA) and the National Ageing Research Institute	Developing an ethical framework for research with ageing culturally and linguistically diverse communities, 2018	Discussion document -focuses on health research in elder migrant communities
Australian Clinical Trials Alliance (ACTA)	Enhancing clinical trial engagement, involvement, and participation for people from culturally and linguistically diverse (CALD) backgrounds, 2023.	Focuses on systems approach to improve access to and engagement with clinical trials
Islamic Council of Victoria	ICV Guidelines for Muslim Community-University Research Partnerships, 2018	Focuses on guidelines for research partnerships. Not publicly available

The Medical Research Future Fund has also developed guidance "Principles for Consumer Involvement in Research Funded by the Medical Research Future Fund"[16] that explicitly states this should include "broad diversity and equity, with the goal of increasing involvement of priority populations through culturally safe and appropriate engagement." However, current guidelines do not adequately address the needs of individuals of migrant and refugee backgrounds and communities to which they belong. In particular, the potential to support decolonising methodologies is not captured in current guidelines.

The decolonising approach to research was first articulated by Indigenous researchers. The central thesis - that the reach of colonialism can still be felt in research processes, structures and methods today - also applies to migrants and refugees, many of whom come from countries which have experienced colonialism. A decolonising approach to research for migrants and refugees might incorporate the centrality of the voice of migrants and refugees, as researchers, as engaged participants, and as creators or co-creators of research priorities and methods.[17]

In line with global pressures and societal change, there is a clear need for Australia to develop and implement specific recommendations for research to ensure that researchers, research institutes and funding bodies can support inclusive, equitable and trauma-informed participation of individuals from migrant and refugee communities.

To identify and explore existing ethical guidelines for conducting research with people with migrant and refugee backgrounds we undertook a systematic review. This has identified a number of guidelines internationally that we have appraised, synthesised the recommendations outlined and identified gaps in current guidelines pertaining to knowledge, practice and research implementation. This review has been submitted for publication and details are outlined in that paper.

The guidelines identified were developed in and for use in a variety of settings and countries across emergency settings with displaced peoples and refugees through to resettlement in high income countries. The guidelines vary in their clear statement of aim, engagement with stakeholders and community, implementation plans, barriers to applicability and clarity of recommendation.

There was an overall consensus that research should include people with migrant and refugee backgrounds in order to support equitable health outcomes with the removal of systemic and/or organisational biases and broader access barriers. The major recommendations outlined in these guidelines are summarised across the themes: (i) empowerment and community participation, (ii) social, health and scientific value of research, (iii) principle of “do no harm”, (iv) respect for rights and dignity, (v) informed consent and (vi) cultural sensitivity.

Conclusion

Australia does not have a national set of guidelines that addresses the needs of those from migrant and refugee backgrounds. There is a growing consensus across communities, health and social care practitioners and researchers that there is an acute need for specific ethical guidelines for research in this area. There is limited national guidance to ensure that conduct of research involving migrant and refugee communities does not exacerbate existing vulnerabilities and does not increase systemic inequity. The National Statement principles of research merit and integrity, beneficence, justice, and respect, require careful and nuanced consideration to ensure that informed consent, privacy and confidentiality, psychological safety, cultural responsiveness and community engagement are incorporated so that, above all, no further harm is perpetrated while conducting research.

An approach of reciprocity, community partnership and engagement are necessary and required. It is also important to ensure other intersecting factors that may increase inequity or risk (e.g. childhood or adolescence) are addressed. Now, is a clear opportunity to co-produce with communities' authoritative guidance that incorporates relevant recommendations from existing guidelines, addresses identified gaps noted and incorporates implementation and evaluation plans. This would promote an inclusive and equitable approach to research and to health outcomes.

Recommendations

1. That the NHMRC support the co-production of ethical guidelines for migrant and refugee populations drawing on the National Statement.
2. That the NHMRC undertake to consider endorsement of such guidelines after they have been co-developed with communities and disseminated among stakeholders for review.

Issues and challenges that may affect undertaking health research with people with migrants, refugees or refugee-like background

1. Socioeconomic, educational and legal status of people from migrant, refugee or refugee-like background
2. Relocation (forced or voluntary), family structure breakdown, communication barriers, transit risks, experience of trauma
3. Disruption of social and cultural support networks
4. Experience of discrimination and racism in the destination country
5. Vulnerability of migrant and refugee communities to potential harm, burden, or undue influence to participate in research
6. Multiple social, economic and political power imbalances between people with migrant, refugee or refugee-like background and research team
7. Researchers and ethics committees may be reluctant to include migrant and refugee communities in a variety of research projects (eg. clinical trials, disaggregation of datasets, qualitative research) due to cultural, language or perceived ethical considerations or barriers
8. Systemic research factors including a lack of language, financial and technical support from the research team may augment the difficulty in participant recruitment and community engagement
9. A lack of understanding of the context of the individual and their community by the research team

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