



# **Ethics and community-based participatory research (CBPR) with people from refugee backgrounds**

## ***Key ethical concerns and principles for CBPR practice***

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This short report identifies best-practice ethical processes in community-based participatory research (CBPR) in the field of refugee studies. Based on a collaborative examination of research ethics in 2019-2020, we offer our combined insights as a resource for community-based participatory researchers and research participants, or co-researchers. Our team of co-researchers from refugee and non-refugee backgrounds in Australia and the United Kingdom analysed peer reviewed CBPR studies followed by reflexive dialogues in each country that explored what does and does not work well in CBPR.<sup>1</sup>

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### **Purpose of this resource**

When working with refugee-background individuals, families, and communities, a reflexive process to discuss ethical concerns is crucial for two reasons:

1. People from refugee backgrounds are not homogenous but are rich, diverse, and constantly changing, with dynamic and complex bonds across time and space. When we assume homogeneity, we risk silencing certain voices—often those at the margins—and ignoring intersectional issues such as gender identity, sexual orientation, age, ethnic, religious, language and educational backgrounds, as well as disability, visa and socioeconomic status.
2. Current guidelines often address high-level concerns but can miss foundational steps. This omission can leave fundamental ethical considerations seriously under-explored.

First, we present eight key ethical concerns to consider when undertaking CBPR. We then outline ten key principles of CBPR that emerged from our reflexive discussions in Australia and the UK in 2019-2020. Given that there is not *one* way to do ethical CBPR, as it will always depend on the partners, context, and the research in question, this resource is designed as a living document, one which we hope will continue to develop iteratively and collaboratively over time.

### **A note on language**

We use the term ***doing co-engaged research*** to discuss CBPR in this project. Doing co-engaged research means that the lived experience expertise of refugee-background researchers is formally acknowledged, prioritised, and celebrated, and that researchers without such lived experience direct their privileges, influence, skills, resources, and their access to systems and structures of power towards this goal.

A second term, ***co-researchers***, commonly used in the literature to situate research participants as joint contributors and investigators, was problematised in our exploration as a form of potentially othering language. The term suggests a distinction between *researcher* and *co-researcher*, raising questions about how those who initiate and fund research may be favoured in this binary. This term should be considered reflexively to be consistent with our thinking on how lived experience expertise is recognised in CBPR. To resolve this, we choose to use the term co-researcher only in situations where it is clear that the term explicitly refers to all members of the research team.

## **Eight ethical concerns in CBPR with people from refugee backgrounds**

Our team's critical reflections on the literature on ethics in CBPR and subsequent dialogues about CBPR with people from refugee backgrounds produced eight key ethical concerns for researchers to consider.

1. **Ethics in practice:** CBPR practitioners tend to restrict their ethical analyses to procedural ethics<sup>2</sup> with an observable gap in analysis of the *micro-ethics* of CBPR in refugee-focused research. Micro-ethics refer to ethics in everyday practice<sup>3</sup>, the micro-dynamics and power fluctuations within groups and communities as well as among researchers, and the everyday and interpersonal risks and benefits of research. An increased focus on micro-ethics in CBPR can facilitate critical analyses of how to maintain integrity in research and prompt the development of even more rigorous and detailed frameworks for ethics in CBPR.
2. **Decolonisation:** CBPR practitioners can harmfully assume that western or Euro-centric theories and approaches are the only valid forms of knowledge. They may un/knowingly impose these ideas onto projects, affecting what, how, and why things are done a certain way, and heavily impacting project outcomes. The impacts and effects of cultural nuances and colonial legacies on (dis)trust, relationship-building, epistemology, and ethics are particularly relevant in CBPR.
3. **Positionality:** CBPR practitioners must ask from the outset and continue to reflect upon: Who is undertaking the research and by what right? Whose agenda drives the collaboration? How might this shape and impact the research, including how it is designed and undertaken, who participates, what is made visible, and what may be rendered absent? Many aspects of identity such as sexuality and queer identities, gender, ethnicity, age, class, disability, and faith, are still ignored in CBPR with people from refugee backgrounds.
4. **Hierarchy:** Hierarchies form for many reasons within a research project, including power and knowledge differentials, resource allocation, and interpersonal dynamics. It is important for researchers to examine whose needs are being served by existing hierarchies, and to explore ways of transforming these hierarchies to ensure consistency with CBPR goals and philosophy. Although perspectives of community-based researchers, academics, contracted researchers, research advisors, people who provide views and information, and funders are likely to differ, CBPR must be accountable to the communities in which the research is conducted, and lead to collaboratively formulating responses to the potentially disparate goals amongst co-researchers.
5. **Competing accountabilities:** Researcher accountability presents a clear but under-addressed ethical dilemma in CBPR with people from refugee backgrounds, in relation to potentially competing interests of funders, academic

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<sup>2</sup> See for example, Karen Block and others, 'Addressing Ethical and Methodological Challenges in Research with Refugee-background Young People: Reflections from the Field' (2013) 26 69

<sup>3</sup> Amy Huang and Megan E Collins, 'Microethics in pediatric ophthalmology' (2018) 22 Journal of American Association for Pediatric Ophthalmology and Strabismus e15

institutions, researchers, community leaders, community organisations and participants.

With respect to *funders as stakeholders*, our collaborative research reflections highlighted that some funders (or funding bodies) expect to be highly involved and can be very directive, seeking to edit or amend findings to support their policy and political interests. The challenge is that funders' views may compete with or supersede the views of the communities in which the research is conducted, particularly regarding desired outputs. As outputs—the outcome of witnessing and documenting lived experience—are so closely connected to relationships with and within the communities where the research is conducted, managing these competing demands requires reflection and critical engagement with hierarchies and power dynamics. There are a range of strategies to address such concerns in CBPR including withdrawal of participation<sup>4</sup>. This raises questions about what happens when competing interests arise and what ethical approaches the research team can use to address these in ways that transform hierarchies and distribute power to people from refugee backgrounds who are involved in the research.

6. **Informed consent:** Issues of consent in CBPR overlap with power dynamics and require deeper exploration in the literature. This includes whether traditional concepts of informed consent from 'participants' (meaning 'research informants') to engage in research is the appropriate model in participatory research involving a range of people from different organisations and backgrounds acting as co-researchers.
7. **Outcomes:** Reflexivity about the impact and outcomes of CBPR is crucial. Collaboration requires sensitivity about the different ways change can be defined. For example, some CBPR projects can create profound personal change, which may not easily be observed or reported but may be as important as institutional or external changes. CBPR projects may yield visible or tangible outcomes and lead to specific actions with observable changes. They may also yield invisible and intangible outcomes. It is important to explore and attend to the widest range of potential outcomes and find ways of witnessing and documenting these.
8. **Reporting on ethical challenges:** While methodological articles *do* acknowledge and describe ethical challenges in CBPR with people from refugee backgrounds, conceptual articles and reports about project outcomes tend not to. Researchers must reflect upon this gap and discuss these issues with honesty and transparency across all forms of research literature.

Our reflections on these eight key ethical concerns informed our team's outline of ten principles for ethical CBPR practice.

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<sup>4</sup> See for example, Milne, E-J (2012) Saying 'NO!' to participatory video: unravelling the complexities of (non)participation. In: Milne E-J, Mitchell, C and De Lange N (eds) *The Handbook of Participatory Video*. Lanham MD: AltaMira Press, pp257-268.

## Ten Principles of CBPR Practice

These ten principles of ethically informed CBPR are, to our knowledge, not brought together in this way across the literature. They extend current thinking and debates on ethics in CBPR with people from refugee backgrounds.

Principles 1 and 2 are the foundation of all other principles, and of ethical CBPR practice:

1. **Cultivate relationships:** Honesty, reciprocity, and respect underpin relationships. It is only when such relationships exist that CBPR practitioners can authentically navigate the 'sticky' ethical issues that can arise in CBPR, that is, relationships that create a space where issues that might be initially perceived as unimportant 'come to matter in ethical ways'<sup>5</sup>.
2. **Witness and document:** The work of CBPR is, in essence, the work of witnessing and documenting lived experience. Active acknowledgement, examination, (re)conceptualisation and critique of these roles are essential throughout projects and should ground all processes and outcomes.

Principles 3 to 10 build upon Principles 1 and 2, and are relevant throughout the CBPR project:

3. **CBPR is human and messy:** CBPR practitioners should be willing and able to be vulnerable and 'sit with the mess' of being uncomfortable. This means being present and open to each other through disagreements, conflicts, and incidents, even those that may constitute a level of risk to researchers<sup>6</sup>. It also means being willing to reveal researchers' humanity and messiness, including sharing stories and experiences among co-researchers.
4. **Share power and control:** A commitment to sharing power and control is key to all CBPR processes and outcomes. This can be challenging to uphold, as funders often require that CBPR practitioners at academic institutions are the keepers of, and administer, project funds and this contributes enormously to power imbalances. Sharing power and control means finding ways to support participants with lived experience to exert agency and control over CBPR projects, resources, and finances.
5. **Honour expertise:** Ethical CBPR honours lived experience expertise, and this has implications for leadership and project carriage, the language used, authorship, and all knowledge production, communication, and dissemination.

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<sup>5</sup> John Mathias, 'Sticky ethics: Environmental activism and the limits of ethical freedom in Kerala, India' (2020) 20 *Anthropological Theory* 253

<sup>6</sup> Caroline Lenette, 'Sitting with the Mess' in Wadds P and others (eds), *Navigating Fieldwork in the Social Sciences* (Palgrave Macmillan 2020)

Honouring lived experience expertise should also guide how CBPR practitioners deploy knowledge, skills, and values across the team and life of the project.

6. **Engender transparency:** CBPR practitioners must ensure that transparency is woven through all CBPR processes and relationships. Transparency is created by clarifying understandings of approaches and power dynamics in the research, understanding the expectations of the individuals and communities involved in the research, and paying attention to those whose perspectives are usually marginalised.
7. **Overcome institutional boundaries:** CBPR practitioners must address and overcome institutional boundaries that tend to compartmentalise and silo knowledge and practice systems. Institutional boundaries interrupt the natural flow of human agency and relationship building. The aim of CBPR practitioners must be to push against institutional boundaries to bring institutional change that places human agency at its centre and that facilitates relationship building among institutions, researchers, and the communities at the centre of CBPR studies.
8. **Cultivate shared understandings:** CBPR practitioners need to attend to the language used in research and do everything in their power to arrive at shared understandings among collaborators of commonly used or popular terms. The commitment to act against using research language in shallow or tokenistic ways in CBPR is an especially important ethical consideration. Scrutiny and avoiding buzzwords are vital, as these can mask unethical conduct and conceal hidden intentions.
9. **Attend to social and power dynamics:** CBPR practitioners need to demonstrate greater sensitivity to social and power dynamics within communities, including those that might marginalise individuals and groups within already marginalised communities. Cultivating a critical, open, and reflexive awareness of power across and within groups is vital in CBPR to avoid silencing and marginalising diverse perspectives and to support wide community representation.
10. **Address micro-ethics:** Foundational strategies, too often ignored, are pivotal to ethically informed CBPR. These include micro-ethical decisions about everyday communication, power, risk, and benefit. Three strategies to prioritise are: (1) accommodating community timeframes in research, (2) providing just remuneration for time, effort, and other expenses incurred by refugee-background co-researchers, and (3) providing debriefing, training, and mutual care to sustain relationships amongst co-researchers and beyond and to ensure the work of witnessing and documenting lived experience proceeds safely. Support is often in place for people within the academy and for industry partners, but we have identified a need to extend and integrate this support for researchers with lived experience who are often at the 'front line' in CBPR projects.

## **Conclusion**

Each CBPR project requires a clear ethical framework with key principles and procedures for decision-making, and these should be included in all published works. One of the first steps in CBPR projects should be to seek and integrate participants' views and perspectives about ethics. These perspectives should then be persuasively presented to ethics committees and other researchers, funding bodies, and/or policymakers.

We hope that this short report outlining key best-practice ethical processes in CBPR in refugee studies will prompt discussions and reflections on issues linked to these key principles in several disciplines. Our aim is to broaden debates and encourage diverse audiences to question taken-for-granted approaches in favour of more equitable, decolonial, and intersectional frameworks.

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