Guidelines for Co-Produced Research with Refugees and Other People with Lived Experience of Displacement

Consultation Report

Tristan Harley and Najeeba Wazefadost

February 2023

About this report

This report compiles into a single document the feedback provided to the [Discussion Draft](#) of the *Guidelines on Co-produced Research with Refugees and Other Displaced People* that was released in November 2022. This feedback was provided by a range of different stakeholders, including refugee representatives, academic institutions, NGOs, international organisations, and researchers with expertise in co-produced research.

We would like to thank the following people for their generous intellectual contributions to this consultation process: Rahul Balasundaram, Brian Barbour, Mohammad Baqir Bayani, Vittoria Catalfamo, Christina Clark-Kazak, Georgia Cole, Diana Essex-Lettieri, Rêz Gardi, Geoff Gilbert, Gül İnanç, Buhendwa Iragi, Evan Jones, Foni Vuni Joyce, Gabriella Kallas, Sabine Larribeau, Caroline Lenette, Hannah Loewith, Jay Marlowe, Daniel Mekonnen, James Milner, Bisimwa Mulemangabo, Sana Mustafa, Louise Olliff, Ana Carolina Pinto Dantas, Laura De Somer, Christoph Sperfeldt, Charlotte Stemmer, Pauline Vidal, and Patrick Wall. Some other individuals with lived experience of displacement also provided feedback to this draft but, due to their ongoing protection risks, chose not to be identified in this report.

This consultation report is divided into two parts. The first part provides feedback relating to the draft guidelines as a whole, while the second part details feedback on each of the different sections of the draft guidelines (using the structure of the discussion draft). Feedback from respondents has been anonymised so that it can be reviewed in an egalitarian manner, without consideration to the seniority of the respondents or the organisations with whom they are affiliated.

Part I: Feedback on the Discussion Draft as a Whole

Reproduction of guidelines

- Several respondents noted the utility of the draft guidelines and suggested that they should also be reproduced in languages other than English. There was also a proposal for an easy-read version to be developed, along with a possible check-list document.

Training exercises

- Multiple respondents suggested that it may be beneficial to prepare an accompanying document that includes some hypothetical training exercises on co-produced research with refugees and other displaced people. This would enable learners to explore some of the micro-ethics surrounding co-produced research and consider appropriate responses.

Refugee perspectives in the document

- One respondent noted that the evidence provided in support of the guidelines draws heavily from academic scholarship, which retains some of the biases that the guidelines seek to address. To help ameliorate this, they suggested including some quotes from leaders with lived experience of displacement throughout the guidelines.

Copyright and authorship

- One respondent noted that the guidelines would benefit from an additional section that explicitly addresses the idea of copyright and authorship. They noted that there are legal, practical, ethical, and epistemological reasons for explicitly making clear who will co-author and legally own the work. Who owns the copyright and control over re-distribution (and at what cost) is fundamental to questions of co-production. A short section which addresses copyright over data (ex. photos in a photovoice project), as well as the research products, with specific reference to open access, would be an important addition.
- In a similar frame, another respondent noted it is important to be clear about who can own what data, where it is stored, and who will have access. They quoted a colleague saying to them 'you have the servers, you take all the data away from here and then we have to ask for it back'. The respondent indicated that in this light we need to rethink the research architectures too.
- A third respondent noted that intellectual property is a real problem in contracted research, and it would be beneficial to address this.

Reflexivity and Positionality

- One respondent suggesting adding a note on positionality. They noted that the draft guidelines allude to the concept of positionality in certain sections but perhaps it would be helpful to have a straightforward point on this. They indicated that this is especially important for co-produced research, where all parties involved should take time to consider what is the social and political context that creates their identity and how this identity influences and biases their perception of and outlook on the world.
- A second respondent similarly noted that that the main reason why co-research fails or is used with ulterior and damaging motives is that academic researchers do not think about the impact of their positionalities and privileges. They suggested that refugee studies is built on white privilege and is full of outsider gazes with racist and ethnocentric undertones as a legacy of colonialism. The respondent suggested that perhaps a series of critical questions to challenge those silences about positionalities and privileges from the start might take the document in a different direction. Otherwise, those power imbalances you refer to are unlikely to change.
- The respondent suggested looking at the work of Linda Tuhiwai Smith and Caroline Lenette in terms of questioning motivations for research. For example, in her article 'Cultural Safety in Participatory Arts-Based Research: How Can We Do Better?', Lenette proposed five questions to assist researchers using participatory methodologies to assess and adapt their practices in culturally safe ways. These questions are: (1) What is your motivation for undertaking the research; (2) What are the origins of your method(s); (3) What needs changing; (4) How do you use methods in culturally safe ways; and (5) How do you know you have achieved your aim?[1]

Advocacy

- One respondent indicated that there could be some section more explicitly focused on advocacy. They indicated that it is peppered throughout, but something about advocacy towards grant

---

[1] Caroline Lenette, 'Cultural Safety in Participatory Arts-Based Research: How Can We Do Better?' (2022) 3(1) *Journal of Participatory Research Methods* 1, 10-11.

bodies so that they support the formative stages of co-producing grant applications, at university administrative structures, at journals and impact evaluation aggregators (e.g. in the UK, the REF), etc. i.e. about who has the responsibility to push for the structural changes that would remove many of the challenges discussed above.

Practice examples

- Multiple respondents suggested that the document could benefit from including some examples of good and bad practices. One idea was to include these examples in the document itself. Another idea was to create a website to host the guidelines and enable stakeholders to contribute their own examples of co-produced research to the website. This latter approach could allow for more detailed practice examples to be showcased.

Language and interdisciplinarity

- Respondents from one organisation highlighted that language/linguistic relativism plays a major role in knowledge production and that there could be more emphasis on the process of translation/interpretation/bilingualism in research publishing. They also suggested that more emphasis could be given on the multidisciplinary backgrounds of the researchers in co-produced academic work in the context of forced displacement.

Contract templates

- Respondents from one organisation suggested that templates for team research contracts could be developed for these guidelines.

Document title

- Given that the guidelines are likely to be endorsed and co-developed by a range of organisations, one respondent suggested naming the guidelines after (or in honour) of an individual to make them more accessible. This could be a shorthand title,

Part II: Feedback on the Specific Sections of the Discussion Draft (as structured)

Purpose

- The discussion draft of November 2022 indicated that the 'guidelines seek to provide clear principles and strategies for consideration by individuals and organisations interested in co-producing research with refugees and other displaced people'.
- Multiple respondents indicated that there needed to be greater clarity in relation to the intended audience of the guidelines. One respondent believed that there was some ambiguity as to whether the guidelines were intended to assist academic researchers to work in more culturally safe ways with refugee-background researchers or whether they are designed for any stakeholder on the principles for genuine partnership. Another group of respondents believed that the purpose could more clearly articulate that it is for both refugee and non-refugee researches.

- Another respondent noted that it may be preferable to refer to 'people with lived experience of displacement' rather than refugees and other displaced people.
- One organisation raised that it may be useful to note that while the guidelines may be drafted in the framework of academic research, the principles are also applicable to (for example) co-produced assessments and evaluations of programming, as well as research roles within ongoing programs or projects.

Key Terms

What is co-produced research?

- In the first draft, the guidelines indicated that 'co-produced research generally refers to research where researchers and those impacted by research work in partnership as co-creators of knowledge'. Several respondents indicated that they felt this definition could be further elaborated to provide additional clarity.
- One group of respondents suggested that different participatory methods could be more clearly explained, along with further explanation of the key players involved in co-produced research (ie (e.g. universities, think tanks, individual researchers, private research entities...) as they have different ways to approach accountability and ethics.
- Another respondent suggested that an additional paragraph could be included to define similar yet different research approaches (ie Participatory Action Research (PAR), community engaged/based research, collaborative research etc).
- A third respondent questioned whether the definition provided suggests a hierarchy between the researcher and the 'impacted by'? They questioned whether it would be better to avoid this by framing it as research produced by researchers, some of whom have personal experience of the subject matter (or similar).

Who are refugees and other displaced people?

- Many respondents have raised issues with the terminologies that were used in the discussion draft for this section.
- One respondent noted whether it may be more inclusive is to describe the context of displacement, rather than specific categories of displaced people, given the way categories can be dehumanising and homogenising. They also noted that the categories discussed do not explicitly mention trafficked people.
- A second respondent suggested that **"**Refugees and other displaced people" may be suggestive of the latter being inferior in some way. They proposed that the term could be replaced with just 'displaced people' (removing the reference to other)
- Another respondent proposed the term *refugees* be used as an umbrella term for all the displaced people who were mentioned in the text including asylum seekers. Alternatively, they suggested that "people in situations of forced displacement" could be used (drawing on the IASFM Code of Ethics) and suggested that the distinction between current and former refugees needs to be mentioned.
- Several respondents suggested that more could be added about intersecting identities (such as gender/sex/age/ethnic/religious and more) and the 'refugee' label being only one of those identities (one which so many reject as suffocating). They suggested that this could contribute to the value of understanding lived experiences from intersectional perspectives.

- Another group of respondents indicated that the current framing inadvertently excludes former refugees and returnees. In some cases, former refugees and returnees might still associate with a displacement identity and there are grounds for their inclusion.
- Two separate respondents suggested that there should be explicit reference to the 1951 Refugee Convention when defining a refugee, rather than including this information in a footnote. One of these respondents also noted that it may be worthwhile to refer to regional definitions in the main text as well. This is in part because persons displaced by generalised violence often are included within regional refugee definitions.
- Another respondent noted that stateless people are not always displaced, and indicated that the framing provided may be misleading. They also indicated there is no reference to disaster displacement here, and that the final sub-phrase 'people who are otherwise displaced' is meaningless and adds nothing.
- In relation to self-identification, one respondent questioned whether it allows people to self-identify in a way that the law would not permit? This could be, for example, as a refugee even within the country of nationality. Alternatively, what if someone were to call themselves a "climate refugee" even though that term is not generally recognised?

Researchers

- Another respondent suggested that the Key Terms section could also include a definition of researchers (as including all who hold and share knowledge) and it could provide more detail about who that might be (e.g., academic researchers, community partners, people with lived experiences etc.). They suggested that this could further challenge white privilege as a determinant of who is an 'expert' or the 'researcher'.

Benefits of co-produced research

Knowledge creation

- One respondent indicated that they felt there should be more included on the realities of co-research, including its challenges, messiness, and politics. They suggested that it is important not to over-state what co-research can achieve, and not to present co-research as the perfect tool that will address everything. The same respondent did not agree that even with a co-research model, everyone is treated with respect, and that there are benefits for all involved.
- A second respondent indicated that there is a need to be cautious in not creating a binary between insider and outsider when discussing the potential benefit of knowledge creation. They indicated that there is literature that goes beyond the insider-outsider dichotomy that encourages more of an intersectional and interactional approach.[2] They suggested that a critical perspective on the notion of 'insider' is important in this section.
- A third respondent indicated that the thought the reference to knowledge creation should be replaced with the term research production at the end of the first paragraph.

---

[2] See Saara Greene et al, 'Between skepticism and empowerment: the experiences of peer research assistants in HIV/AIDS, housing and homelessness community-based research' (2009) 12(4) *International Journal of Social Research Methodology* 361; also, Edward Ademolu, 'Birds of a feather (don't always) flock together: Critical reflexivity of 'Outsiderness' as an 'Insider' doing qualitative research with one's 'Own People'' (2023) *Qualitative Research* (forthcoming).

- A fourth respondent suggested referring to religious background and intersectionality (when discussing 'cultural background'. A fifth respondent suggested changing this language to 'and the unique intersections of identity to which they reside in'.

Real-world impact and evaluation

- One respondent indicated that rather than referring to evidence-based recommendations in this section, it could be preferable to refer to evidence-based advocacy.
- A second respondent suggested that co-production can also inform other academic users of the most up-to-date and accurate analysis, contributing to a more valid perspective in the relevant disciplines.

Skills development and collaboration

- A group of respondents indicated that while they agree that co-produced research might lead to skill development, it can go further and create new opportunities within the field that might grant more power, skills and resources to refugee researchers, who might be in a better position to navigate power imbalances in research (e.g. access grants...).
- Another respondent noted that it would be beneficial to not that it is not just the development of new skills, but also he strengthening of existing skills. They also questioned whether something should be mentioned about empowerment.

Key Principles

Joint ownership

- One respondent suggested that the language 'towards those being researched' at the end of paragraph 1 be replaced with 'towards those most directly concerned and affected'.

Benefits for all involved

- One respondent flagged that there are interesting considerations around reciprocity that could be unpacked further, such as who gets to determine the exchange and what constitutes mutual benefit.
- Another respondent suggested adding explicit reference to academic networks when referring to social networks. They also noted that an additional benefit can be access to opportunities to further academic reputation/scholarship/publication.

Inclusion and respect

- One respondent suggested replacing the words 'treated with respect' with 'respected as a knowledge producer'. They also suggested going further than enabling all voices to be heard, suggesting they should also have a tangible influence on the outcomes too.

Accessibility

- A group of respondents indicated that they felt that the subsection on accessibility should be expanded to better reflect the barriers that refugee researchers face in accessing research projects, and in contributing meaningfully. They indicated that creating access in a context of power imbalances involves many steps. For instance, one key condition of accessibility is the extent to which the institutions' admin department is willing to be flexible to accommodate the specific needs of refugee researchers, especially when the legal environment is restrictive (e.g. sending money, flexibility with the legal status etc).
- A second respondent raised whether there should be specific mention to language in this section.
- A third respondent suggested also including reference to a 'epistemically safe environment' where alternative perspectives are accorded full consideration. They noted that this could also be mentioned under inclusion and respect. Similarly, another respondent suggested 'mentally safe' as alternative language.

Ongoing ethics of care

- One respondent indicated that they felt 'ethics of care' needed to be defined in this section. They noted that there is an emerging literature on care ethics in forced migration but there is also a misunderstanding of what ethics of care means. They suggested considering Christina Clark-Kazak's recent article '"Why Care Now" in Forced Migration Research? Imagining a Radical Feminist Ethics of Care' as an entry point that summarises some of the literature and proposes ways to operationalise care ethics in forced migration studies.
- Another respondent noted that there could be reference to the "do no harm" (DNH) principle and associated methodologies in this section (or under safety). They suggested that it is key and perhaps broader than what is stated. They noted that the main purpose of DNH is to avoid exposing people to additional risks – advertently or inadvertently – through program/research interventions or actions. This requires looking at the broader context and mitigating negative effects on affected populations and environments. Too often, research is undertaken in a manner that exposes participants/collaborators and puts them unnecessarily at risk. Researchers should be sensitive to and take account of the vulnerabilities and safety concerns of those with whom they collaborate in the research process. They noted that co-produced research is uniquely placed to identify such risks and adopt strategies to prevent harm.

Safety

- One respondent indicated that it may be useful to refer to Florencia Luna's work on the concept of vulnerability, which she describes as one of layers rather than labels.[3] In thinking about vulnerability this way, researchers can remove potential layers of vulnerability by having informed study designs by the communities.

Transparency and trust

- One group of respondents indicated that this section should highlight that trusts needs to be built not only at the project team level, but also at the institutional level. They noted that co-

---

[3] Florencia Luna, 'Elucidating the Concept of Vulnerability: Layers Not Labels' (2009) (2)1 *International Journal of Feminist Approaches to Bioethics* 121.

produced research might be promoted by some researchers but might not be supported by the entire institution. This may lead to harmful dynamics (e.g. another member of the research team questioning the inclusion of refugee researchers, unsupportive admin...).

- Multiple respondents suggested that the idea of support to researchers with lived experience needs to be further clarified. One respondent noted that to many refugees, research may infer a powerful academic entity coming in, and as such they may not feel comfortable sharing their lack of full understanding of the processes, or why things need to happen a certain way to be academically sound. They raised whether capacity-strengthening could be flagged.

Co-produced Research in Practice

Is co-produced research the right approach?

- One group of respondents indicated that they felt that reference to refugee leadership in research was missing in the paper. They stated that an external reader might interpret that co-produced research is always the best case scenario (compared to outsider researchers conducting the study). However, an alternative is to transfer power, skills and resources to individuals or groups of refugees to lead studies themselves (and take all decisions). They suggested that co-production and refugee leadership in research are both valuable, and co-creation might be a step towards more refugee-led research. To rectify this omission, this group of respondents proposed mentioning transfer of resources to a refugee-led research group as an alternative to co-produced research in this section.
- One respondent noted that there is a need to be careful about how we can address situations where time/budget are used as excuses to not co-produce research

Setting the Research Agenda

- One respondent suggested that the idea of 'expectation setting' could be explored when looking at setting the research agenda. This would also impact the evaluation of the research impact.

Recruitment

- One respondent noted that it is also important to note that during vacancy advertisement, it should be advertised on the platforms and through the networks that are accessible to the people with forced displacement.
- A second respondent asked whether it would be suitable to directly address the issue of interpretation, and the expectation there can often be for people with lived experience to conduct interpretation and translation as part of their role (without necessarily this being included in job descriptions or agreed upon).
- A third respondent flagged whether transparent processes are always suitable in the context of co-produced research. They noted that many persons with lived experience may be in a position to recruit or might be an expert already known by researchers, for example. They asked whether that person be subject to a transparent process while other research members are not and would this be the best use of resources instead of adding that person from the start, as many research projects normally do.
- A fourth respondent noted that due to the nature or context of some research, public advertisement might not always be feasible - particularly in risk or hard to reach settings.

Recognition and remuneration

- One respondent indicated that the discussion surrounding work permits needs to be further elaborated. They noted that it is not that refugees and other displaced people cannot work but it could be deemed illegal for them to do so. They indicated that understanding the jurisdictions that research occurs is imperative
- One group of respondents noted that considerations around remuneration will be different for refugee researchers, a group of refugees involved in a participatory study, or even intermediaries (such as mobilisers, enumerators, or translators).
- Another respondent indicated that there are also related questions about whether the researcher is considered an "employee" with corresponding insurance and employment benefits.
- Another respondent highlighted that HR systems need to be sensitive to the challenges of registering individuals to be paid, or in reimbursing ad hoc payments, in ways that aren't patronising or excessively delayed. They also noted that fair and timely payment, and appropriate contracting vs ad hoc arrangements, is also important for showing that those involved in co-producing knowledge are properly valued, protected and remunerated

Undertaking ethics review

- One respondent noted that that ethics committees predominantly relate to procedural ethics. The complexities of co-design require an ongoing ethics in practice. To address this, the respondent indicated that it may be worthwhile to flag that while ethics approval from a university, government or health-based institution may be a starting point, it may very well be insufficient in responding to the contextual and dynamic processes associated with co-design, particularly in displacement contexts.
- Another group of respondents indicated that this section should be expanded to discuss situational ethics more fully, such as how they should be dealt with in practice, and who takes final decisions while in the field.

Training and support

- One respondent questioned whether this section should be titled 'knowledge sharing', given that it is broader and more two-way directed than training.

Reporting and disseminating the research

- One respondent suggested adding reference to the effort that needs to be made to disrupt the idea that paywall journals are necessarily more rigorous and prestigious.

Authorship and recognition

- When discussing what should be considered when identification is not possible, one respondent suggested that it might be worth noting that providing an explanation of this nature is also an opportunity to educate the audience of the research output as to the precarious realities faced by displaced people.

- A second respondent noted that, in addition to the risks to team members involved, the risk to the group to which the refugees or other displaced persons belong must also be factored into all decisions in this matter. Anonymity may not be enough.
- A third respondent questioned whether it may also be worth mentioning the growing practice of journals asking for, or accepting authorship/contribution statements.
- Two other respondents commented on the structure of this section. They both noted that this section almost overlaps with the recognition and remuneration, and it might be useful to merge or have 'Authorship and remuneration' as sub-sections of recognition.

Evaluating research impact

- One respondent noted that links to co-design could be made in the section on evaluating research impact to ensure that it is informed throughout (and not just a knee jerk reaction at the end of a project).
- A second respondent suggested adding the following text at the end of the first paragraph: 'In all cases, this risk must be clearly set out before the research bid is made and then again before the actual research is undertaken'.
- A third respondent noted that evaluation involves adequately budgeting to support the 'afterlife' of a project, including 'expert by experience' researchers who do not, like lots of academics (albeit not precarious ECRs), continue to get paid after the project ends to keep working on it. They suggested that the principles of 'ethical closure' of a project seems really important here.

Additional Resources

- One respondent suggested adding the book *Documenting Displacement* edited by Katarzyna Grabsksa and Christina Clark-Kazak to the resource list.
- A second respondent suggested reviewing the book *Values and Vulnerabilities: The Ethics of Research with Refugees and Asylum Seekers*.
- A third respondent referred also to the practice guide on the co-production of research between academics, NGOs and communities in humanitarian response that was published by Michelle Lokot and Caitlin Wake.