

## The ethics of research with structurally vulnerable people in humanitarian settings – Research Briefing

### Headline Messages

- There is a diversity of research undertaken by external researchers with structurally vulnerable<sup>i</sup> people in humanitarian settings. These researchers are located in academic institutions, international bodies (such as the UN), International Non-Governmental Organisations, and governmental entities.
- There is no absolute entitlement to research, and external researchers should be prevented from engaging in unethical research ‘tourism’ that delivers no or limited demonstrable benefit. As a minimum, it is important that researchers do no harm, and do not promise or insinuate that there will be direct benefits from the research.
- It is imperative that the research profession (including researchers, educators, employing organisations, institutional review boards and funders) take action to prevent unethical external research.
- Existing ethical guidance and mechanisms are insufficient to prevent poor quality and harmful research including studies that exploit local partners and participants.
- High level ethical guidance is required, which has uni-disciplinary, multi-disciplinary and transdisciplinary relevance, and which encompasses relational, professional and procedural ethics. This guidance should be grounded in human rights principles and be co-produced by all research actors engaged in humanitarian settings.
- This is an under-theorised area that would benefit from public discourse and research.
- Institutions and funders need to robustly evaluate the impact of researchers on structurally vulnerable people in humanitarian settings. This evaluation should include feedback from participants’ representatives such as grassroots NGOs; and involve safe communication channels for researchers and other interested parties to raise concerns. Funders and other decision makers should listen to concerns from researched populations, even if these concerns have not reached a threshold requiring a formal intervention such as the threat of a lawsuit. Further, institutions and funders can develop additional risk mitigation measures such as closer review and analysis of data (real time check-ins). Such engagement should be calibrated to identify ‘repeat offenders’.
- Foundational and continuing research training in the ethics of sensitive research is required to cultivate ethical sensibility<sup>ii</sup> in the design, delivery, and ongoing ethical scrutiny of research.

### Overview

Strategic action on the ethics of research with structurally vulnerable people in humanitarian settings is timely and urgent; particularly against the backdrop of the UK government’s decision to make immediate and swingeing cuts to research funded through the overseas development budget<sup>iii</sup>.

Research and data are significant resources for humanitarian, fragile and conflict impacted communities. They can be used to investigate, to record, to inform, to direct, and to persuade; that is to deliver evidence-based, transformative change. Expenditure that delivers limited or adverse impact is not what researchers, funders or research audiences want to occur. It is wasteful and

reputationally damaging to the research profession; and can lead to exhaustion, withdrawal and cynicism amongst communities. Worse still, unethical external researchers returning repeatedly to the same people can do harm, retraumatising participants, and preventing them from evolving their identity beyond the violence experienced. Repeated studies with the same small sample, in controlled or fabricated settings constructed by local gatekeepers, risk inaccurate findings.

There are a range of professional ‘types’ of unethical external researchers characterised by Elliott (2021) as:

- the well-intended but unconnected (for example researchers without professional or personal connection to a research site motivated by the desire for their research to create change)
- the well-intended and connected (for example members of a research site’s diaspora)
- the prurient, and
- the ambitious (who weave a ribbon development of humanitarian research into a career path of qualifications, positions, publications and grants).

Although ethical mechanisms, guidance and training are in place, there is still extremely poor practice happening. Structurally vulnerable people are essentialised as ‘just wanting their story told’. However, this denies agency: people may want their stories to be told, but it matters *who* tells it, and *how* they tell it. Researched populations report being tired of exploitative mining and re-construction of their narratives for no notable change in circumstances. Ultimately, communities ‘shut down’ from researchers – and this hurts both the population and the evidence base.

There are systemic weaknesses in external funder and academic organisations’ oversight. There are contextual challenges in humanitarian settings that are:

- infrastructural (for example the absence of national ethics committees),
- attitudinal (for example commonsensical assumptions about the impossibility of basic ethical practices like securing informed consent), and
- material (for example local gatekeepers’ reliance on research funding, and local academics reliance on international associations).

More broadly there are the challenges for researchers of openly discussing both unethical, unprofessional and harmful practice, and also the emotional labour involved in undertaking sensitive research. Due to their less secure status, early career and contract researchers may consider such open discussion to be risky in terms of undermining their professional reputations or reducing the likelihood of future employment.

This is a critical conversation that needs to involve researchers at all career stages, institutional review boards, funders, and local gatekeepers as well as researched communities. Researchers from conflict-impacted, humanitarian, and fragile settings should play a leading role given their professional and lived experience insights. Full participation will require a recognition of power dynamics, a shared research literacy, and respect for the agency and voice of less powerful, structurally vulnerable actors.

## The contribution of ‘sensitive research’

The growing field of sensitive research is a theoretical and practical resource for this endeavour. The development of sensitive research has benefited from substantial contributions from feminist and social science methodologies including through the ‘scholarly activist’ tradition, which stresses the

importance of the researchers' identity, location, standpoint and ongoing self-reflexivity. The [Research for Health in Conflict – Middle East North Africa](#) study will include training in its open access online training programme 'Research Methods for Mental Health in War and Conflict' (launching in 2021).

Research may be socially, politically or ideologically sensitive for research participants and for researchers. (However, whilst having an awareness of the potential sensitivity of undertaking research on a topic, with a group, or in a context, it is important not to presume that such research is automatically sensitive.)

The exact definition of sensitive research varies between texts. Authors such as Lee (1993) have focused on it being a broad type of research that is accompanied by an intrusive threat because the research asks participants to reveal information about a deeply personal experience within their private sphere. Other authors have focused on the sensitivity of a topic as being related to the likely impact of the research. For example, Dickson-Swift et al. (2016) suggest that sensitive subjects are likely to evoke distressing emotions for the participant. While Sieber and Stanley (1988, p49) suggest that 'socially sensitive' research is that in which "there are potential consequences or implications, either directly for the participants in the research or the class of individuals represented by the research".<sup>iv</sup>

Research with structurally vulnerable people in humanitarian settings aligns with these range of sensitivities. Conducting unethical research raises risks for all parties in the research encounter not only participants and researchers, but also gatekeepers, interpreters, transcribers and administrators. Creating an ethical sensibility enables researchers, supervisors, institutional review boards and funders to identify unintended consequences. The following section on Human Rights Based Research illustrates the application of selected principles to practice.

## Human Rights Based Research

The Office of the High Commissioner for Human Rights published a 'Human Rights Based Approach to Data' as part of the Sustainable Development agenda<sup>v</sup>. It outlined the following Principles: participation, transparency, accountability, privacy, self-identification and disaggregation. These principles are not abstract or technical. Rather, they can be applied readily in a meaningful and granular manner to research practice in humanitarian settings. Likewise, these principles can be applied to systemic measures such as ethical guidance.

### Participation

- Recognise participants' agency and respect their right not to participate. Do not 'harass' (cajole, wear down) potential participants or local gatekeepers to achieve recruitment and access. Be culturally sensitive to the ways people say no that may be different than one's own.
- Involve communities in identifying relevant and valuable research questions and designing culturally sensitive, contextually appropriate methodology.
- Negotiate ethical partnership with local actors.
- Negotiate exchange for participants' expertise such as presentation of findings in an accessible form that is useful for the researched group's understanding and advocacy, institution strengthening, learning opportunities, and access to decision makers.

## Transparency

- Be open with gatekeepers and participants regarding the purpose of the research, its intended outcomes, and the likelihood of impact.
- Be clear about researcher's own role and positionality that is the degree of influence within the study's power structure. More broadly, be honest about the extent of influence the research will have with decision makers including in their own institution and country or region.
- Do not claim that there will be research benefit – either specific (to the participant) or generalised (to the community, society) - if this is not confirmed.

## Accountability

- Be critically reflexive about the purpose and value of research. If a study has no benefit other than satisfying the researcher's curiosity, achieving a qualification or securing funding then do not do it.
- Sanction researchers who undertake unethical research.
- Deliver on feedback and exchange commitments.

## Recommendations

The complexity of the ethics of research with structurally vulnerable people in humanitarian settings requires action at strategic and practice levels by a wide range of actors. Whilst systemic change will be achieved through the actions of institutions, funders and employers, supervisors and researchers can achieve meaningful and immediate change within their spheres of influence.

## Institutions and Funders

- Initiate the development of high-level ethical guidance on research with structurally vulnerable people in humanitarian settings informed by the following approach.
  - Co-producing with all actors engaged in research with structurally vulnerable people in humanitarian settings including academic institutions, funders, communities, professional bodies, and research audiences;
  - Embedding human rights principles of participation, transparency, accountability, privacy, self-identification and disaggregation;
  - Drawing on sensitive research theory and practice to maximise benefit and minimise risk of research for both participants (individuals, groups and societies) and researchers;
  - Creating mechanisms that facilitate researchers to be open about harm in research practice;
  - Creating systems for ongoing scrutiny of research practice; and
  - Including sanctions by funder, institutional and / or professional body.
- Fund research into the factors that lead to unethical research with structurally vulnerable people in humanitarian settings, the processes and practices that enable, and the measures that will curb these practices.
- Remove the ability of unethical researchers to cloak or make opaque unethical research and avoid ethical scrutiny.

## Employers

- Create a supportive leadership culture in which the impacts of undertaking sensitive research are openly discussed (giving researchers 'professional permission' to speak about their practice), and addressed through a learning, no-blame environment and the provision of professional training.

- Provide a 'decent work' environment that addresses the health and safety issues raised through the undertaking of sensitive research including normative provision of mental health support and therapeutic supervision.
- Understand that sensitive research can impact staff other than researchers for example administrators, transcribers and make appropriate health and safety provisions.
- Establish confidential feedback mechanisms for employees, particularly early career and contract researchers, to raise concerns regarding unethical or harmful research.
- Develop institutional-level protocols regarding sensitive research, embedding good practice in the governance structure and financial decision-making system proposed at the outset of the research design process.

### Supervisors

- If appropriate, sensitively explore the researcher's motivation for working in a particular area of sensitive research.
- Work with researchers to ensure that outcomes are meaningfully designed; and develop opportunities that allow them to influence the impact of the research.
- Assist researchers in the management of emotions that emerge during the work by using examples from the literature and, in particular, by engaging them in the concepts of emotional labour.
- Acknowledge the fundamental tension within the supervisory/managerial relationships of researchers in which researchers must juggle their commitment to the research subjects and those of the funders.
- Arrange regular/periodic check-ins on data to ensure work is being done ethically.

### Researchers

- Acknowledge that research may have an emotional impact in ways that are not anticipated or easily rationalized.
- Recognise that particular methodologies and methods may lead to more sensitised research encounters and data.
- Cultivate self-reflexivity by keeping a research diary to track ongoing areas of concern, identify particular areas of vulnerability and monitor the emotional impact of the research and responses to participants and the context.
- Seek out both formal and informal opportunities to debrief, where it is possible to freely discuss emotional reactions without fear of professional consequences.
- Ask for supervisory guidance in identifying external, professional peer networks with other researchers undertaking similar research. Consider establishing a formal community of sensitive topic researchers with whom to share their concerns and dilemmas.
- Recognize and allow room for change in questions and topics once one is in the field.

### Further Reading

Hilario, AP and Augusto, FR (eds) 2020 [Practical and Ethical Dilemmas in Research Topics with Populations Considered Vulnerable](https://www.mdpi.com/books/pdfview/book/3052) <https://www.mdpi.com/books/pdfview/book/3052>

Krause, J The ethics of ethnographic methods in conflict zones. *Journal of Peace Research* 2021 1-13  
<https://journals.sagepub.com/doi/pdf/10.1177/0022343320971021>

Mallon, S and Elliott, I The Emotional Risks of Turning Stories into Data: An Exploration of the Experiences of Qualitative Researchers Working on Sensitive Topics, *Societies* 2019 9(3) 62 <https://doi.org/10.3390/soc9030062>

Mallon, S and Elliott, I What is 'sensitive' about Sensitive Research? The sensitive researchers' perspective. *International Journal of Social Research Methodology* 2020 <https://doi.org/10.1080/13645579.2020.1857966>

Small, ML De-exoticizing Ghetto Poverty: On the ethics of representation in urban ethnography. *City and Community* 2015 14(4) <https://onlinelibrary.wiley.com/doi/abs/10.1111/cico.12137>

## Acknowledgement, Logos

This research briefing is informed by the webinar: '*Parasitic Swallows*' *Experiences of doing research with 'vulnerable people' in humanitarian settings* (March 2021). Panellists: Dr Iris Elliott FRSA, Visiting Scholar Department of Sociology, University of Cambridge; Dr Sharon Mallon, Open University; and Dr Randa Serhan, American University of Beirut; and with a personal contribution by Dr Ammar Azzouz whose tweet on this issue went viral with supportive engagement from African, South American, European and North American countries.

[https://twitter.com/Dr\\_Ammar\\_Azzouz/status/1372927683059986440](https://twitter.com/Dr_Ammar_Azzouz/status/1372927683059986440)

'Parasitic swallows' is a term coined by Dr Elliott to describe the external researchers who seasonally migrate to her home, Northern Ireland, and undertake research without providing any benefit to research participants or their society; and perhaps doing harm, retraumatising, preventing people from evolving their identity beyond the conflict. This is discussed in her input to the webinar.

<https://r4hc-mena.org/blog/>

Recording of the webinar is available [here](#).

---

<sup>i</sup> This research briefing uses the term 'structural vulnerability' to describe those constrained by social and political forces (Thorjussen and Wilhelmsen 2020 in Hilario and Augusto 2020). It avoids categorising persons in humanitarian settings as inherently vulnerability in recognition that this essentialising individuals and negates their agency. Further, such automatic categorisation risks labelling, stigmatising, objectifying and marginalising individuals and groups, potentially leading to disempowerment.

<sup>ii</sup> See Cecchini (2020 in Hilario and Augusto 2020) for a discussion of ethical sensibility; "A pre-requisite for making ethically appropriate choices is that researchers pay attention to and are able to identify ethically delicate moments, which may not always be straightforward." (p54)

<sup>iii</sup> <https://www.universitiesuk.ac.uk/news/Pages/govt-must-urgently-reconsider-research-budget-cuts.aspx> [Accessed 30 March 2021]

<sup>iv</sup> Mallon and Elliott (2020)

<sup>v</sup> A Human Rights Based Approach to Data - Leaving No One Behind in the 2030 Agenda for Sustainable Development. Guidance Note to Data Collection and Disaggregation (NB *available in: Arabic Chinese English French Russian Spanish*).

<https://www.ohchr.org/Documents/Issues/HRIndicators/GuidanceNoteonApproachtoData.pdf>