A participatory action research partnership aimed at minimising and managing moral distress among frontline research staff

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Brief description of context

We would like to discuss an approach to establishing and running a research partnership focused on an essential but neglected ethics and social justice concern in global health research: How international research programmes can ensure fairer research processes that protect frontline staff from moral distress. The goal of the partnership is to advance policy, practice and understanding of this neglected area and to contribute to fairer research conduct, a more inclusive and creative research culture, and strengthened health and research systems. There will be three broad inter-related work packages: a) better characterizing moral distress among frontline research staff and designing tools to explore and measure it; b) co-designing and iteratively implementing and evaluating ways of working and promising interventions; and c) developing guidance outlining responsibilities and practical approaches/actions targeting funders, research leads and science/ethics reviewers[i]. At the heart of the work is a 'frontline staff network' which brings together frontline staff and their immediate managers from a diverse set of research settings and networks (socio-political, institutional, study design(s) and funder(s)). This research collaboration was formally established through an in-person meeting in Oxford in March 2025, with participants and proposed work primarily from Africa and South East Asia. We used participatory approaches to understand the ethical challenges experienced by frontline staff, to share experiences of positive practice to build upon, and to agree on ways to work together into the future.

In this meeting we would value the opportunity to share and get input on the outputs and agreements from the meeting (including around the ethics issues faced, good practice, and interventions and activities to undertake together into the future). We would also like to discuss and get input into the participatory approach we have used to date and how we plan to evolve the partnership moving forwards. Specifically, we would like to discuss the strengths and limitations of the approach in building equitable partnerships, within the context of the funding call and ongoing global funding shifts.

Discussion of ethical issues

Current research ethics discussion and guidance focus on the protection of research participants and communities, and – increasingly – on safeguarding and the promotion of fairness between institutions. The emotional well-being and justice-related concerns of frontline staff who play vital roles in global health research is largely overlooked [1]. Working in constrained health systems, and typically with precarious employment and little power in research programmes [2], these staff can experience serious moral distress. There are disagreements in the literature on what constitutes moral distress, its' drivers, experiences, measurement and appropriate interventions [3]. However it is generally understood to be the emotional and cognitive reactions following events which clash with someone's moral code, values or expectations, arising where there are moral uncertainties, tensions, conflicts or dilemmas, or 'when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action' [4]. Moral injury can arise where sustained moral distress leads to impaired function or longer-term psychological harm, potentially producing guilt and shame, and in some cases also a sense of betrayal, anger and profound 'moral disorientation'. The systems drivers of moral distress and injury highlight the importance of organisational responsibility and response [5].

The emotional challenges that frontline health workers face globally are increasingly recognised as moral distress or injury, contributing among other factors to high levels of reported stress and 'burnout' among health workers [8], with adverse implications for staff well-being, mental health, team relationships, absenteeism, retention, quality of care and patient outcomes [9]. Unchecked, moral distress can contribute to 'moral neutralisation' whereby staff become too discouraged to show moral sensitivity, where they normalize or justify unethical behaviour, or where they become morally indifferent [4]. Given the systems drivers of moral distress, such neutralization can be a form of coping strategy in deeply challenging contexts [10], feeding back into communication and relationship challenges with colleagues and patients/family members, as part of a vicious circle.

Frontline research staff working in health systems are embedded in the same emotionally challenging, stressful contexts as health workers (e.g. when supporting a clinical trial and conducting surveillance work), and there are grey areas and overlaps between research funded frontline staff and locally employed health workers in roles, salary support and accountability responsibilities. Research on the challenges and emotional distress faced by frontline research staff working in LMICs [2, 9, 13, 14, 15,16] has raised a key justice concern: the inadequacy of support processes for the staff who make up the 'frontline' of global health research and who often have least power, voice and access to resources in large research programmes. However there is little research on emotional well-being and moral distress more specifically, and how this differs across different research projects, contexts and categories of frontline staff (by type of study, whether facility or community based, by socio-cultural, political and institutional context, and by gender, age, and level of training of staff) [1]. There is also little practical guidance for research leaders and funders on how research might be set up and support processes organised to minimize and manage moral distress among these frontline staff.

We are a funded research partnership centred on minimising and managing moral distress among frontline staff because we see this as i) a justice concern, as frontline staff are at the sharp end of distress while more senior people in research teams benefit from their 'moral labour' [18], ii) an ethical concern, as moral distress has implications for respect in collaborations with research colleagues, participants and communities and iii) a practical concern, as research and care quality (and therefore value and uptake of health research findings) will be undermined if essential staff are suffering moral distress. The focus of the research partnership is on organisational responsibilities and processes, including links to psychological support initiatives, as opposed to individually focused mental health or resilience training interventions. The focus is also on low-and-middle-income settings where research participants, who may be severely ill, often receive their health care from chronically stressed health-workers in over-stretched and under-resourced health systems. In these settings the whole concept of moral distress may differ significantly from more resourced environments, as may be the responsibilities and opportunities to intervene and support.

Conclusions and recommendations

In this November meeting we would value the opportunity to share the outputs and agreements from our initial network meeting, with a focus on ethics issues experienced as shared through a series of artists' reflections and rich pictures. These include a rich picture created by participants on the impacts and implications of recent global funding shifts for frontline staff. We would also like to share suggestions for good practice emerging from a world café activity, which focused on three types of support processes which had been prioritised from a longer list by the meeting participants: 1) Ethics reflection sessions (including variants on 17); 2) Other team support processes and 3) Clear and fair policies for work and professional development.

Regarding the establishment and functioning of the research partnership, we will discuss and seek input on the participatory approach we used to establish the network, and the participatory methods we used in our initial meeting. We will also share the approach to conducting participatory action research around promising organisational interventions and how we hope these will feed into institutional policy and practice, in the short and longer term. Finally, we would like to discuss the strengths and limitations of our approach to building equitable partnerships, within the context of the funding call and ongoing global funding shifts.

References

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[i] The initial research proposal was written by SM, based on past work and formal and informal engagement with colleagues, collaborators, community members and research staff while living in Kenya for 27 years; support and input that has continued since shifting base to Oxford in 2020 to date.