**Barriers to global health: The challenges faced by non-governmental organisations from low and middle-income country settings in getting research published**

Authors; **Vishal Gadre** ([vishalg@wctindia.org](mailto:vishalg@wctindia.org)), Wildlife Conservation Trust, 11th Floor, Mafatlal Centre, Nariman Point, Mumbai-400021, India; **Vijay Tate** ([vijay@wctindia.org](mailto:vijay@wctindia.org)), Wildlife Conservation Trust, 11th Floor, Mafatlal Centre, Nariman Point, Mumbai-400021, India; **Michael J.C. Reid** ([Michael.Reid@durhamcollege.ca](mailto:Michael.Reid@durhamcollege.ca)), School of Interdisciplinary Studies, Durham College, Oshawa, Ontario, Canada; and Canadian Cameroon Ape Network, Toronto, Ontario, Canada; **Chetan Trivedy** (Corresponding author – [c.trivedy@qmul.ac.uk](mailto:c.trivedy@qmul.ac.uk)), Blizard Institute, Queen Mary University of London, London-E1 2AT, United Kingdom; Wildlife Conservation Trust, 11th Floor, Mafatlal Centre, Nariman Point, Mumbai-400021; and Brighton and Sussex University Hospital, NHS Trust, United Kingdom;

**STATEMENT OF SUBMISSION**

We confirm that the submission is an original work and it is not under consideration for publication in any other journal. We have not made similar submissions in the past. There are no competing interests or funding support.

**ABSTRACT**

NGOs and other non-academic agencies play an increasingly important role in providing access to healthcare in LMICs. These organisations generate important data that can be developed into published research. The inclusion of published research by NGOs, especially from LMICs, has been limited in peer reviewed journals. Focusing on issues surrounding research governance such as ethical oversight; we recommend modifications to current approach by medical journals which make viable efforts to de-colonise global health by adopting a more inclusive and pragmatic approach to increase the academic visibility of NGOs and non-academic agencies.

**KEY WORDS**

Non-governmental Organisations; Low and middle-income countries; Ethics; Research; Global health

Non-governmental organisations (NGOs) and other not-for-profit agencies play an important role in supporting health projects in low- and middle-income countries (LMIC) (1).These groups bridge the shortfall in government facilities by providing access to medical care in communities that may otherwise lack them. In India alone, over 3 million NGOs were reported in 2017; with 60% working in rural regions, and over 90% working on issues related to population health (2). Many of the NGOs working at the grass-roots level generate data from routine activities. These data may include health interventions, feedback from community-groups, and other reports (3). NGOs use such data to identify and prioritize population-health needs, evaluate and improve service-delivery, and create resources for training and advocacy. While this may not be seen explicitly as planned research, sharing this work would allow academic and governmental bodies to gain access to data from hard-to-reach populations facing inequities in healthcare; and benefit local communities, NGOs, and the advancement of knowledge.

The provision of formal research opportunities for NGO staff could help build capacity to collect, manage, analyse, and disseminate data in a systematic and ethical manner. Encouraging NGOs to publish and share first-hand operational knowledge would facilitate a better understanding of local health systems and the cost-effectiveness of the interventions. The increased visibility via peer reviewed publications could promote upscaling of activities via increased contributions from competitive grants and donor agencies which often require publications and base their decisions on ‘value for money’ (1,4,5).Peer reviewed publications would also increase the accountability of NGOs by ensuring that outputs are scientifically valid, are based on robust and ethical methodology, and contribute to current knowledge.

NGOs, especially those working in LMICs, are often under-represented in the peer reviewed publications of research findings (4,6). NGOs are traditionally not designed for academia leading to differences in the perceived definition, mandate, and benefits of research which may act as barriers to publication (1,4).Editorial boards too often perceive that NGOs as non-academic institutions lack a scientific approach to study design, ethics, and data management. This may result in submissions from NGOs being rejected by mainstream journals because they do not fit into the traditional peer review model, which may result in the reduced visibility of an NGOs’ contribution to science. Most medical journals demand a stringent ethical oversight to safeguard the human participants from potential harm. However, the requirements deemed necessary for ethical conduct of research may pose additional challenges for NGOs working in LMIC settings. Lack of research funding and limited access to formal ethics review boards may further hamper the ability to plan research as a part of routine NGO activity; which may result in a negative impact on their service delivery.

The constraints in which NGOs operate, particularly in LMIC settings, may not allow for the allocation of resources and systems necessary to adhere to the publishing standards set by academia with a predominantly global-north perspective. Evidence of power-inequities between NGOs and research institutions also exists; wherein the latter hold power by providing ethical reviews and clearances (4). Recently there has been much discussion about de-colonising global health by increasing number of publications led by authors from LMICs (7). Although ‘open access’ policies may increase the access to research publications; the academics from LMICs are often prohibited from publishing due to unaffordable costs for publishing – especially for resource-poor NGOs from LMICs. Some journals do encourage submissions from LMIC authors by aiding in scientific writing suited to respective journal style, along with the subsidisation or waiving of publication fees for open access articles. However, such waivers are often based on the World Bank classification; which could provide an unrealistic assumption on affordability of publication fees by NGOs (8,9).

NGOs should be encouraged to invest resources to build research-capacity in their workforce via creating infrastructure and training opportunities, while also securing collaborations with established research institutes to facilitate manuscript submission and help navigate the ethical review process. To accomplish this, there must be greater equity between global North and South in terms of opportunities for scientific contribution. Hence, while ensuring quality and ethical propriety in any medical research is essential; it is imperative that the contributions from NGOs are a part of efforts to improve global health.

One of the biggest challenges that NGOs face in publishing research is access to formal ethical review. One solution adopted by Médecins Sans Frontières (MSF) was to establish their own ethics committee to ensure that all research was scientifically valid and ethical. Their model identifies four basic principles: respect for persons; beneficence; nonmaleficence; and justice as proposed by the ‘Declaration of Helsinki’ and the ‘International Ethical Guidelines for Biomedical Research Involving Human Subjects from the Council for International Organizations of Medical Sciences’ (10,11). MSF also argues that retrospective analysis of data collected during routine program activities be exempt from ethical review provided these basic criteria are met (12). This discussion highlights the need for workable solutions to support NGOs’ participation in publishing research. Better signposting and providing clear practical guidance for NGOs to submit work to academic journals is urgently needed (13). A more pragmatic approach would be for the journals to appreciate the challenges faced by NGOs; and develop a more inclusive model which looks beyond the western perspectives when setting ethical research standards. Creating collaborative local/regional ethical review systems specifically for research activities involving NGOs and academic partners may aid in this process.

Editorial boards should review their policies and provide support for NGOs and other non-academic partners to publish, especially those from LMICs. Overhauling the traditional approach to the ethics review process by better engaging non-academic institutions; by active inclusion and engagement of NGOs through representation on editorial boards. We also call for development of clear guidance and training packages specifically for non-academic/NGO partners in order to raise the standards of research. It would be a key step in recognising the potential these organisations have for contributing to our scientific knowledge with regards to global health.

**REFERENCES**

1. Delisle H, Roberts JH, Munro M, Jones L, Gyorkos TW. The role of NGOs in global health research for development. Health Res Policy Sys. 2005;3(3). doi: 10.1186/1478-4505-3-3.
2. Das N, Kumar R; Public Health Foundation of India. Role of Non-Governmental Organizations in Healthcare Sector of India. 2016. doi: 10.13140/RG.2.2.30420.19845.
3. Piotrowicz M, Cianciara D. The role of non-governmental organizations in the social and the health system. Przegl Epidemiol. 2013 [cited 2021 Jan 11];67(1):69-74, 151-5. Available from: <https://pubmed.ncbi.nlm.nih.gov/23745379/>
4. Masefield SC, Megaw A, Barlow M, White PC, Altink H, Grugel J. Repurposing NGO data for better research outcomes: a scoping review of the use and secondary analysis of NGO data in health policy and systems research. Health Res Policy Sys. 2020;18. doi: 10.1186/s12961-020-00577-x. PubMed PMID: 32513183; PubMed Central PMCID: PMC7278191
5. NGOs and the challenge of impact investing: creating value and doing good. Klynveld Peat Marwick Goerdeler (KPMG). 2018 August [cited 2021 Jan11]. Available from: <https://assets.kpmg/content/dam/kpmg/xx/pdf/2018/08/ngos-and-challenge-of-impact-investing.pdf>
6. Kareithi RN, Lund C. Review of NGO performance research published in academic journals between 1996 and 2008. S Afr J Sci. 2012;108(11/12). doi: 10.4102/sajs.v108i11/12.755.
7. Lawrence DS, Hirsch LA. Decolonising global health: transnational research partnerships under the spotlight. International Health. 2020 Nov [cited 2021 Jan 11];12(6):518–23. Available from: <https://doi.org/10.1093/inthealth/ihaa073>
8. Lawson S. Fee waivers for open access journals. Publications. 2015;3(3):155–67. Available from: <https://doi.org/10.3390/publications3030155>
9. The World Bank [Internet]. Data; c2021 [cited 2021 Jan 11]. World Bank Country and Lending Groups. Available from: <https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups>
10. The PLoS Medicine Editors. Ethics Without Borders. PLoS Med. 2009;6(7), doi: 10.1371/journal.pmed.1000119.
11. Council for International Organizations of Medical Sciences. International Ethical Guidelines for Biomedical Research Involving Human Subjects. 2002 [cited 2021 Jan 10]. Available from: <https://cioms.ch/wp-content/uploads/2016/08/International_Ethical_Guidelines_for_Biomedical_Research_Involving_Human_Subjects.pdf>
12. Médecins Sans Frontières (MSF). MSF Research Ethics Framework - Guidance Document. 2013 [cited 2021 Jan 11]. Available from: <https://fieldresearch.msf.org/handle/10144/305288>
13. International Committee of Medical Journal Editors. Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly work in Medical Journals. 2019 [cited 2021 Jan 11]. Available from: <http://www.icmje.org/icmje-recommendations.pdf>