Investigation of Ethics Dumping Cases at Galter Library

By Mohammad Hosseini & Adam DiMascio

Mohammad Hosseini, PhD, is leading an international and multidisciplinary effort to create more awareness about ethics dumping, which happens when researchers seek out lenient Institutional Review Boards (IRBs) and ethics committees to conduct ethically problematic research. The project team is reviewing reports and identifying instances of researchers based in high-income countries (HICs) who conducted ethically problematic research in low- or middle-income countries (LMICs) that would not have been approved in HICs. This practice is also observed in domestic collaborations where researchers based in well-resourced institutions conduct ethically problematic parts of their research in under-resourced institutions that may adopt a lenient approach towards ethics in order to attract funding or participate in collaborative research.

After receiving a grant from the Global Young Academy (GYA), this work started at Galter Library in January 2024 in collaboration with researchers Muhammad Zaffar Hashmi, PhD (The University of Lahore, Pakistan), Leila Niamir, PhD (International Institute for Applied Systems Analysis, Austria), Estrella Diaz Sanchez, PhD (University of Castilla-La Mancha, Spain), Sandra López-Vergéz, PhD (Gorgas Memorial Institute for Health Studies, Panama), Laura Margottini (The Bureau of Investigative Journalism, Italy) and Adam DiMascio (Research Intern, University of Chicago). The project will identify and explore ethics dumping cases to develop a database, which will be openly shared with the research community to create more awareness about and deter ethics dumping.

This project will produce three deliverables. First, a database containing ethics dumping cases. Second, a survey that will be distributed among GYA members to collect information about more possible cases of ethics dumping that have either not yet been widely reported or are reported in languages other than English. Third, a synthesis of the cases concerned to be submitted to a peer-reviewed journal and public media. Thus far, members have completed a review of Trust Project deliverables, a PubMed keyword search, and have reviewed several case books such as "Ethics Dumping Case Studies from North-South Research Collaborations," and "Ethical Issues in International Health Research," published by the World Health Organization.

Challenges:

Gathering data on ethics dumping cases can be challenging for several reasons. Since ethics dumping is a relatively new term, it lacks a widely recognized or standardized definition in the literature. It is likely that some researchers reporting ethics dumping cases have used different terms to describe them. Another challenge pertains to confidentiality. IRBs and other institutional actors that might be aware of ethics dumping cases have a duty to keep information about applications confidential. Some casebooks are anonymized, and do not provide specific information about cases. For instance, they might note that a case has taken place somewhere in Southeast Asia without naming the actual country or involved institutions, impeding efforts to corroborate details of ethics dumping cases with several resources. Furthermore, all cases found by this project are those that have been reported in English. Hosseini and his team hope that surveying the GYA members can help rectify this discrepancy.

Insights:

One common thread through cases of ethics dumping is a lack of proper informed consent. This is exacerbated by the fact that ethics dumping disproportionately impacts members of locally marginalized communities (women, indigenous peoples, and sex workers were harmed in explored cases). Within the context of the country or region where ethics dumping occurs, subjects may not be as adequately represented or protected by IRBs or research enterprise and governments at large. Furthermore, ethics dumping sometimes concerns complex or high-mortality conditions within medical research (e.g., HIV and other sexually transmissible diseases, cancer). Admittedly, though, this might be partly because available casebooks exclusively report ethics dumping cases in medical contexts.

This work was presented in February 2024, during the annual meeting of the Association for Professional and Practical Ethics (APPE) in Cincinnati. The project team is looking forward to future opportunities to share their research including accepted presentations at the forthcoming GYA annual meeting at the National Academy of Sciences (DC, May 2024) and the World Conference on Research Integrity (Athens, Greece, Jun 2024).

How can you help?

If you know of any ethics dumping cases, please feel free to contact the project PI at mohammad.hosseini@northwestern.edu.