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Viewpoint

When ethics and politics collide in global health research

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When ethics and politics collide in donor-funded global health research

By Katerini T. Storeng and Jennifer Palmer

Introduction

In this viewpoint, we share our experience of censorship in evaluation research for global health. Our story shows a broader trend of donors and implementing partners' deliberate uses of ethical and methodological arguments to undermine essential research. In a context of chronic underfunding of universities and their growing dependence on donor-driven research grants, we propose several structural and cultural changes to prevent manipulation of research governance systems and to safeguard the independence of research.

Censorship is a strong word. But what else can you call it when a donor that commissions a research-based evaluation of one of its major global health programmes instructs the researchers to omit important results from their final report? Or puts pressure on them to change the tenor of their conclusions? Or when a staff member of an implementing partner being evaluated threatens the reputation of the researchers and their university if they publish negative findings?

Such interference in any research process is antithetical to independence. Agencies commissioning evaluation research, which tends to have an immediate and practical use for decision-makers, often engage public health universities to study their programmes. They rely not only on universities' methodological and subject area expertise but also on their strong systems of research ethics and governance, recognising that compliance with such systems is essential for ensuring that the evidence produced adheres to "the highest standards of integrity"¹. However, current systems primarily protect vulnerable research subjects from powerful researchers and are ill equipped to deal with challenges when researchers are less powerful than research subjects.

A case study of censorship

We experienced some of the limitations of current systems in research ethics and governance within an evaluation of a programme funded by the United Kingdom's Department for International Development (DFID). With a budget exceeding £140,000,000, the programme aimed to reduce deaths from unwanted pregnancies in 14 countries in Africa and Asia through policy and service delivery interventions.² These were implemented by the leading international reproductive health NGOs Marie Stopes International (MSI) and Ipas. The evaluation research, commissioned by DFID, was carried out by an international, interdisciplinary consortium led by the London School of Hygiene and Tropical Medicine (LSHTM), with which we are affiliated.

DFID considered the implementing NGOs "stakeholders" of the evaluation whose involvement was desirable "so long as the objectivity of the study is not compromised."¹ MSI and Ipas therefore had the opportunity to comment on our study protocol, broker our access to informants and documents, and preview research outputs for fact checking. DFID and the NGOs considered this important because of the "risks" the outputs might pose to the programme within socially conservative countries.

In practice, staff at the NGOs' headquarters used this stakeholder involvement to obstruct aspects of the evaluation in various ways, not least when, at the end of the contract, we sought to disseminate policy research findings to academic audiences. In addition to requesting changes to tone and content, they demanded that we anonymise their organisations and ideally, the target countries, claiming our findings could be "weaponized" by their political opponents to derail policy change. Other times, however, the NGOs simply stated they wanted to be unnamed because they disagreed with our "positions and conclusions".

In addition to making these demands, senior NGO staff met with the Chair of the LSHTM's ethics committee, which had approved the research protocol, to voice "concerns" that we had not followed appropriate procedures for obtaining informed consent. Later, in a coordinated move, three individuals from both MSI and Ipas retroactively withdrew consent for using their specific contributions in our research after our academic articles had already undergone favourable peer review.

The accusations resulted in a thorough investigation by the university's Research Governance and Integrity Office, charged with ensuring that researchers comply with relevant regulatory requirements, including ethical protocols. While under investigation, we withdrew scheduled conference presentations and halted our publications.

The university concluded we had adhered to good research ethical principles, but that we must anonymise the NGOs because our protocol had promised to protect individuals' identities and, "where appropriate", that of their organisation. Although we had intended this clause to allow individuals to discuss sensitive issues without having to divulge their institutional affiliation, the ambiguity in this wording initially prompted the ethics committee to *extend* that protection to these powerful organisations. The practical consequence was to sanction the NGOs' wish to control which findings we could make public.

We felt that the NGOs had used the research ethics framework to censor our work, and therefore appealed the university's decision. We argued that anonymising organisations and countries would make it impossible to substantiate our analysis and that the claim to harm was exaggerated, designed mainly to obstruct our publications. We also felt strongly that it was in the public interest to be transparent about the identity of recipients of public funds and about their programmatic practices, a principle that DFID has committed to publicly.¹

We also turned to senior staff at DFID to protect our independence, but they dismissed our request for a meeting, saying they could see no merit for DFID "to interfere in a 'he said she said' situation" and referred us back to the ethics committee.

Eventually, we were able to publish one of the disputed academic articles³ after the Research Governance and Integrity Office concluded that we were not required to conceal the identities of the organisations being evaluated, provided that the data used came from public domain sources or participants who had not withdrawn consent.

Many other findings, however, remain unpublished. The final evaluation report,⁴ published nearly 18 months after its first submission, contains only a condensed summary of evaluation findings, while DFID annexed the detailed country policy analyses reports into sections that will remain internal. Meanwhile, partly due to the intimidating environment, other researchers have hesitated to publish full analyses that are ambivalent about the programme's overall effectiveness. As a result, a substantial reservoir of learning generated by more than 20 academic researchers over a five-year period is not available to the public, including to implementers and external evaluators of the follow-on programme funded by DFID.

A pattern of interference

Although we present only one case study, similar dynamics play out between other public, private and philanthropic donors and researchers who undertake evaluations and other commissioned global health research.

Numerous colleagues have described similar forms of interference at different stages of the research process, resulting in "tick-box evaluation" designed to please donors, reports that have been "shelved"

or “embargoed”, and “bartering” about which findings can be published. Often such interference is couched in the language of ethics; other times donors and their implementing partners attack the rigour of research methodology or discredit researchers’ interpretations as “naïve” to pressure them to suppress findings and analyses that cast programmatic strategies and outcomes in unfavourable light.

Although some academics have gone public with their experiences,^{5,6} most such cases remain unknown, which shows how demanding it is for individuals to confront strong institutional interests in the nexus between funders, NGOs and universities.⁷ For us, it would have been easier to acquiesce to the pressure we experienced. Being accused, in effect, of ethical malpractice was an ordeal, and by speaking out, we risk future funding, career progression, and co-optation by the anti-aid agenda.

Such risks are pronounced within a landscape marked by chronic underfunding of universities and reliance on soft funding through short-term, donor-prioritised research projects, where the stated or tacit threat of withdrawing support for future contracts can influence published findings.⁸ Meanwhile, donors are under intense pressure to demonstrate that their ‘investments’ deliver results. As such, it can be difficult for all parties to withstand the pressure to contribute to positive bias in support of ‘success stories’ about programmes and interventions,⁹ even when the consequence is misrepresentation of what is working and how public funds are used.

Necessary changes to protect researchers’ independence

Uninhibited debate on the behind-the-scenes dynamics of research and evaluation is overdue. Both structural and cultural changes are needed to confront what has recently been called the “success cartel” in global health,¹⁰ and to prevent external actors’ manipulation of university research regulations to control what are not solely ‘ethical’ but also political issues.

DFID is a leading global health funder, which, despite the challenges we have experienced, is notable for committing significant resources to generating learning from its programmes, including in controversial areas that other donors avoid. Yet DFID and other donors must be clearer towards implementing partners that, no matter how sensitive the topic, they will be subject to independent evaluation that will be made public.

Better systems for redress are necessary for researchers whose independence is threatened, particularly in the ethically hazy area of ‘evaluation research’ where the political economy of the evaluation process can have such a distorting effect on findings. This should include fully independent research project management committees that can arbitrate conflicts of interest, as exist for clinical trials. Universities should expand the remit of existing committees, establish new ones or, ideally, appoint an independent ombudsperson to consider how to better balance protection of organisations’ interests and the public interest,¹¹ as specified in the UK Economic and Social Research Council ethical guidance.¹²

Ultimately, universities have a duty to contribute evidence to public policy-making and to protect academic integrity. Fulfilling this duty will depend not only on stronger research governance frameworks to safeguard independence, but also on directly challenging the power of external donors that enables them to interfere in the research process.

Authors' contributions

Both authors conceptualised and wrote the manuscript.

Declaration of interests

We declare no competing interests.

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