

Ethical Considerations of Dissemination and Restitution of Findings in Global Health Research

ÉTUDE DE CAS / CASE STUDY

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Résumé

Cette étude de cas porte sur les obligations éthiques concernant l'étendue et la portée des stratégies de dissémination et de restitution des connaissances dans un contexte de recherche en santé mondiale.

Mots clés

dissémination des connaissances, restitution des connaissances, application des connaissances, transfert des connaissances, éthique, recherche en santé mondiale

Summary

This case study discusses ethical obligations regarding the extent and scope of knowledge dissemination and restitution strategies in the context of global health research.

Keywords

Knowledge dissemination, knowledge restitution, knowledge translation, knowledge transfer, ethics, global health research

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Conflit d'intérêts

Patrick Gogognon, coordinateur pour l'[Axe éthique et santé des populations](#), a diffusé le concours d'étude de cas, mais n'a pas été impliqué dans l'évaluation de cette étude de cas, ni dans son classement dans la compétition.

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Conflict of Interest

Patrick Gogognon, coordinator for the [Axe éthique et santé des populations](#), publicised the case study competition but was not involved in the evaluation of this case study nor in its ranking in the competition.

Introduction

Conducting health research often requires the use of local resources, such as infrastructure, equipment, and the time and energy of professionals. Research participants also dedicate time and can take risks by sharing biological specimens and/or sensitive information. In low and middle income countries, where health systems are already fragile, the diversion of limited health resources for research may represent important opportunity costs for local populations. Sharing the benefits of research can be considered a form of compensation to participants and their communities (1). Moreover, Emmanuel *et al* (2, p.932) state that "... research must have social value, through generation of knowledge that can lead to improvements in health; without social value, research

exposes participants to risks for no good reason and wastes resources”. The authors argue that global health studies can enhance social value by disseminating results in appropriate languages and formats to key stakeholders, including the local community, health policy makers, health-care providers, and international health-care organizations (2).

Regulatory agencies and conventions on ethical research increasingly promote the restitution of findings to participants, and dissemination of findings to stakeholders. For example, on restitution, the Declaration of Helsinki, Article 33, states that: “... patients entered into the study are entitled to be informed about the outcome of the study and to share any benefits that result from it, for example, access to interventions identified as beneficial in the study or to other appropriate care or benefits” (3). On dissemination, the Declaration of Helsinki, Article 30, stipulates that “... results should be published or otherwise made publicly available” (3). Similarly, the Canadian Tri-Council Policy Statement asserts that “Final reports shall be made available to the territorial or organizational community or community of interest participating in the research” (4). By adhering to these ethical principles, funding agencies are increasingly requiring the inclusion of short descriptions of dissemination strategies in research proposals. For example, a 2013 call for proposals launched by the United States Agency for International Development (solicitation number WASH2013-002) required a half page plan for the dissemination of results. These plans, however, often do not require comprehensive details on the specific activities and tools that will be used to reach different audiences (e.g., participants, community representatives, policy makers, researchers) (5).

Although knowledge transfer appears to be accepted as a necessary means to promote the social value of global health research, there is less agreement within the academic community on researchers’ ethical obligations regarding the appropriate extent and scope of dissemination and restitution strategies to be used. In the absence of clear ethical norms, it is more difficult for researchers and authorities, such as research ethics boards and funding agencies, both to establish coherent objectives with regards to dissemination and to evaluate the adequacy of the activities implemented.

In practice, the deployment of strategies to disseminate and retribute research findings is often left to the researchers’ goodwill and discretion. Researchers may choose to limit their dedication to dissemination activities for different reasons including lack of personal interest, allocation of funds towards other research priorities, or time constraints. Some may focus on publishing research findings in high impact English-language journals because this is highly rewarding for career advancement. However, costly journal subscriptions and language differences may limit local stakeholders’ access to the results. Other researchers may be keen to conduct more extensive knowledge translation activities that go beyond the scientific arena. However, they can encounter challenges that limit the effectiveness of their well-intentioned activities. These challenges may arise from having to translate scientific jargon into lay language, to overcome peoples’ negative attitudes towards research, to collaborate with people from different disciplinary backgrounds, to deal with decision makers’ lack of interest, or to reach all targeted groups (6,7).

In order to be comprehensive, dissemination and restitution activities require significant time and resources (6-8). However from an ethical perspective, it is unclear how much effort researchers should devote to ensure that results and potential benefits of a study have been appropriately shared. The following case study aims to generate discussions on what global health researchers actually owe participants and their communities with regards to knowledge transfer.

Presentation of the case study

John, a young Canadian researcher, received a grant to conduct an epidemiological study on the effects of malaria on child development and school performance in a francophone West African country. The study was approved by the research ethics committee of John’s institution and the host

country's Ministry of Health. A consent form was signed by all participating families, stating that: "*the results of the study will be used to promote malaria prevention policies in West Africa*". Part of the initial budget was allocated to pay for a publication in an open access scholarly journal.

The data collection phase was a success. Local teachers and nurses helped John conduct the study. The population reacted well to the study, resulting in a high participation rate despite the blood testing sessions and the long questionnaires touching upon sensitive issues.

About two years after the data was collected, John and his team successfully published the results in a high impact, peer-reviewed English-language journal. This journal was selected because it was deemed more prestigious than some of the open access journals in global health. In addition, John had realized that the project no longer had the necessary funds, approximately \$3,000, to pay the fees to publish their article in a high-quality open access journal. Unfortunately, this meant that the results of the study were less likely to be shared with the participants and other key stakeholders where the study took place. A few members of a local university were able to access the published article and understand the scientific terminology.

After hearing of the study, a local non-governmental organization (NGO) working on malaria control contacted John to ask him to share the article. Before sending it, John remembered that he did not have the copyrights to the article and that the journal did not provide free reprints. Sharing the article would be a breach of intellectual property law.

Instead, John and his colleagues sought additional funding to organize an in-country workshop with local stakeholders. With the resources available, John organized a one-day workshop in the capital of the country hosting the study. Attendees were representatives from the Ministry of Health and selected medical staff, teachers and NGO workers. John recognized most of them because they had contributed, directly or indirectly, to the data collection process. Each attendant received handouts of the PowerPoint presentations that summarized the study's results using attractive graphs. A few outspoken participants asked questions to clarify medical terms and interpret the statistical models. At the coffee break, the representative of the Ministry of Health, who had delivered the plenary lecture, excused himself due to his busy schedule, after receiving his *per diem* (for a discussion of how *per diem* might be undermining research in developing countries, see (9)).

A few days before leaving the country, John also managed to organize a press release with the local media to present the findings. On the way to the airport, John was shocked when he caught, by the glimpse of his eye, the title of the local newspaper's headline: "*New Canadian Research Shows Malaria Makes Our Children Dumb!*". John was frustrated by the media's misinterpretation and oversimplification of the research findings. He feared that the local communities would react negatively to how they had been portrayed in the article and that some individuals, fearing stigmatization, might refuse to participate in the next assessment phase that he was already planning. As John embarked on the plane back to Canada, he began to reflect on what he could have done at the outset to more effectively share the results of the study and make them useful for the implementation of malaria prevention policies in West Africa.

Questions

1. What do researchers owe participants and their communities with regards to restitution and dissemination of research findings?
2. Did John meet his ethical obligation to retribute and disseminate research findings? If not, what could (or should) he have done differently in order to better share the results of the study, for instance, during the preparation of the study, the publication process, the organization of the workshop and the press release?

3. How should researchers identify and prioritize the target audiences for dissemination?
4. Which parties should be responsible for the dissemination of the findings in this case?
 - What should be the role of ethics committees in this regard?
 - How can awareness of the importance of dissemination and restitution be raised amongst other responsible parties?
5. How can the issue of funding constraints in global health research be reconciled with the ethical obligations to incorporate effective dissemination plans that are accessible and useful for the different audiences?
6. Can it be desirable, from an ethical standpoint, to withhold sensitive findings from participants? If so, how should researchers disseminate and retribute research findings that are of a sensitive nature?

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