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Consent Documentation and the Accessibility of Research Results in International Development Research

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Cette étude de cas touche les problèmes qui peuvent survenir lors de la recherche sur le développement internationnal, avec des réflexions basées sur des expériences de recherche au Pérou. Les questions à l'étude concernent d'une part les différences culturelles dans le processus de documentation de consentement et d'autre part la préoccupation des retombées de la recherche au profit des participants.

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ÉTUDE DE CAS / CASE STUDY

Consent Documentation and the Accessibility of Research Results in International Development Research

Erika Malich¹

Résumé

Cette étude de cas touche les problèmes qui peuvent survenir lors de la recherche sur le développement internationnal, avec des réflexions basées sur des expériences de recherche au Pérou. Les deux questions à l'étude concernent les différences culturelles dans le processus de documentation du consentement et la préoccupation des retombées de la recherche au profit des participants.

Mots clés

Pérou. documentation de consentement, international, résultats de recherche, accessibilité, asymétrie de results, accessibility, power asymmetry pouvoir

Abstract

This case study touches on issues that may arise in international development research, with reflections based on experiences conducting research in Peru. The two issues to be discussed are that of cultural differences in the consent documentation process, and ensuring that the benefits of research flow back to research participants.

Keywords

développement Peru, consent documentation, international development, research

Introduction

It is important to understand the research context when considering the ethical implications of international development research. This may require research design and implementation to account for specificities of the local context and the broader implications arising from power imbalances between researchers and research participants. Considering the ethical implications of participant consent and data collection procedures is crucial, however, it is also important to consider the ethical dimensions to data dissemination and accrued benefits. Key ethical issues inherent in any type of research become apparent when working in contexts as a 'foreign researcher', and the issue of power asymmetries are particularly important to consider when conducting field work [1].

Case Presentation

This case reflects on ethical issues based on a project about the accessibility of research knowledge for policymakers in Peru. The accessibility of research refers to users being able to access and understand research knowledge, which is important to increase the use of evidence in practice. This project underwent ethical review by the Advisory Council for Research Ethics (ACRE) at the International Development Research Centre (IDRC), and was carried out in accordance with the Canadian Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, 2nd edition (TCPS2). After a thorough search, it was not apparent that any additional local Peruvian ethics requirements applied to this project.

Field work was conducted during June and July of 2016 in the cities of Lima, Piura, and Areguipa. Primary data was collected through semi-structured, in-depth interviews with educated individuals including researchers, communicators, and policymakers. The aim of the study was to build an understanding of what accessibility of research knowledge means for both researchers and policymakers in Peru, and to find opportunities for it to be increased.

Documenting Consent

In certain types of research it is possible that a researcher may be working in a context that is not well known to them. In addition, it is possible that there will exist power asymmetries between the researcher and the research participants. Both of these factors may necessitate different types of research design and protocol. The obligation to obtain free, informed, and sustained consent is recognized internationally by many research ethics policies. In the TCPS2, it falls under the principle of respect for persons, where Article 3.12 states that "evidence of consent shall be contained either in a signed consent form or in documentation by the researcher of another appropriate means of consent" [3].

Documenting consent in a culturally and contextually relevant way is important. In this case, as the project was dealing primarily with educated professionals, we felt justified in using a signature as part of the consent process, which was provided in Spanish, the participants' language. Through the course of the interviews, it became apparent that the practice of signed consent forms was not common-place for participants. While not all participants reacted, some viewed it as a necessary irritant (laughing about the rules "from Canada"), all the way to lauding the process as commendable and wanting it to be replicated. One interviewee in particular, a university researcher, had this to say about the informed consent process before the start of the interview.

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Well, what has impressed me to start is the [informed consent] protocol. Yes, because I have given various interviews [in the past] and the most they have asked me is 'can we audio-record you?' and I have permitted the recording, but [the informed consent form] – it seems we should replicate it.

In different contexts, or with different subsections of a population (e.g., vulnerable groups, indigenous populations), different types of consent documentation procedures may be more appropriate. For example, one might consider audio-recorded consent or thumb-print consent for illiterate populations. There are many different ways that a researcher may legitimately document consent, and different options should be explored, taking into consideration the particular research participants and the cultural context. Local norms, including local legal requirements, need also be considered when selecting the best documentation method(s). The responsibility to understand the context and the research participants before deciding on the best method for documenting consent is the shared responsibility between the researcher with the support and guidance from their Research Ethics Board (REB).

Benefits to Participants

Another issue to consider is ensuring that research benefits flow back to participants. Researchers should, at a minimum, aim to ensure that their research is not "extractive" in nature. Extractive research refers to "research practices that extract knowledge from communities to the benefit of people elsewhere and leave communities unchanged or worse off than they were before" [5]. Aiming to make sure benefits of the research flow back to participants is one way to achieve this, however, depending on the type of research being conducted, other methodologies can be used to further minimize extractive research and work towards empowerment [5].

Sharing knowledge and learning with participants is important. In the TCPS2, in <u>Chapter 4</u>, this would fall under the principle of "equitable distribution of research benefits", where it states that:

Researchers should ensure that participating individuals, groups and communities are informed of how to access the results of the research. Results of the research should be made available to them in a culturally appropriate and meaningful format, such as reports in plain language in addition to technical reports [4].

The nature of the 'accessibility' of research results, however, will vary in different contexts. Additionally, in most circumstances, research should also be made accessible beyond just research participants, but also to their communities of practice as well.

Some participants in our study raised the issue of not being able to benefit from previous research done in their contexts, or even being able to access it. This was particularly the case for those located outside the capital in less-resourced regions of the country. One university professor in Piura captured the idea well: "It happens frequently for us that we find studies and theses in foreign universities on us... A thing like you are doing, and then nobody knows". Another participant discussed the same issue even in the case of Peruvian researchers: "there are renowned Peruvian researchers that publish articles in foreign journals, and you know that they are there but you have to pay [to access them]." For these two participants, lack of finances and language barriers made accessing international journals difficult.

Researchers should therefore take the accessibility of research dissemination very seriously, as this is an ethical (and moral) responsibility. One possibility to increase accessibility is through publishing in an open access format, thus not requiring a user to pay to access the material. Researchers can also consider additional techniques to create even greater accessibility. As suggested by Smith, "there are diverse ways of disseminating knowledge and of ensuring that research reaches the people who have helped make it. Two important ways not always addressed by scientific research are to do with 'reporting back' to the people and 'sharing knowledge'" [6]. These techniques could include alternate publications of research results in plain (and local) languages, and in a culturally appropriate format, to both increase access for participants and to reach a broader audience.

It is the intention of our project to have any outputs exclusively in open access formats (this journal included), as well as providing results in English and Spanish where feasible, to increase the accessibility to research participants. Participants that indicated interest in the available place on their consent form will also be sent a plain language summary of the research findings in Spanish, along with other outputs of the project including blog posts (the results summary was not yet sent to participants at the time of writing).

Conclusion

Taking into consideration the specifics of both the cultural context and power asymmetries is important to document consent in a culturally appropriate way, as well as to assure that benefits return to research participants. When there exists the potential for power asymmetries between the researcher and research participants, it becomes important to consider these with great care. While this case study has only touched on two particular considerations, many other ethical dimensions exist that should also be considered. A researcher will be better placed to conduct ethical research if they are mindful of the context they are working in and make a proactive effort to respect, and ensure benefits flow back to, their participants and their communities.

Questions to Consider

- 1. What level of familiarity with a context is necessary to understand the best method of documenting consent?
- 2. What different ways can participants benefit from different types of research? What is the level of obligation from the researcher to ensure that these benefits are received?
- 3. Is it ever ethical to conduct 'extractive' research? How can researchers aim to avoid conducting extractive types of research?

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