

Case Study 1

Conflicts in consent: An ethical dilemma concerning research at a medical field site

Disclaimer: The ethical determination reached here is separate from, and does not include a consideration of, any formal legal actions. Neither is it an official recommendation by the AAPA Ethics Committee nor the AAPA itself. It is an exercise in working through an ethical dilemma by using the RICE guide to tease apart a complicated, yet potentially common, situation.

INTRODUCTION

This scenario was submitted to the AAPA Ethics Committee after a call went out to the AAPA community in March, 2016 requesting scenarios for case study development. An Ethics Committee Fellow used the scenario to create a case study in the format of the RICE Guide, found in Whiteford & Trotter's (2008) *Ethics for Anthropological Research and Practice**. The RICE Guide is a problem-solving guide for determining the courses of action that could be taken by a researcher faced with an ethical quandary. RICE is an acronym for Reflect - Investigate - Contemplate - Evaluate. Throughout the case study the RICE Guide's prompts and questions are listed and responded to.

The Ethics Fellow engages with this scenario from her own, first-person perspective. The author's background is as a biological anthropologist who studies paleopathology and human osteology in historic skeletal samples.

SCENARIO

A major field site is located in a rural area of a very low-income country. Local residents are primarily employed for wage labor through the field site, though some travel for work in other areas. The research site is tied to the medical clinic due to cross-use of medical equipment. Thus, the field site is the primary/only source of medical care for individuals living within a large radius. Study participation rates are very high as a result.

CASE STUDY

Reflect: Identify your own values and biases

- What are your feelings about the case?
- What are the sources of your intuitions (i.e., your moral training, professional norms, personal history, social position, religious beliefs, relationship with the people involved, etc.)?
- What are the limitations on your objectivity?

Upon initial reflection, my feelings were that even if made explicit that the availability of medical care is not conditional upon study participation, there might still be a feeling of obligation that would negate completely voluntary informed consent. If not all attendees of the field site for medical care are employed, then the ones who are not employed may feel less obligated to participate in the study. At the same time, however, this research study being the only source of medical care is likely also an obstacle to true voluntary consent. My feelings are based upon well-established professional norms that emphasize free, informed consent without undue coercion or influence. Other sources for my reaction to this case scenario come from an

awareness of past instances of exploitation in fieldwork, inside and outside of anthropology, without truly informed or freely given consent. Many of these instances came to my attention through previous coursework or professional discussion. I also find that the codes or statements of ethics from national professional organizations are useful resources. Specifically, I have referred to the *American Anthropological Association's* statement on ethics, the *American Association of Physical Anthropologists'* code of ethics and ethics resources page, and the United Nations Universal Declaration of Human Rights, but there are many other resources available from a variety of sources.

Identifying personal bias is an important part of any research and varies highly depending on the situation and involvement. As a biological anthropologist who focuses on historic human skeletal remains, I do not have any direct experience designing or implementing medical or cultural research in the field such as is described in this situation, so I may be missing practical knowledge that would inform on this study or the nuances of freely given consent. However, as an outsider not personally invested in the research at the medical facility, I might be more objective than if I were involved in this research and wanting it to succeed.

In this area, as well as all others in this document, it is important to identify how you, the reader, vary personally in your feelings and experiences that would inform your perspectives relating to this case study scenario from my own presented here.

Investigate: Probe the facts as presented

- What other information is relevant to the ethics of the case?
- Are other possibilities/resources available?
- Has any perspective been neglected?
- Are there unanswered questions?

The scenario presented is concise, providing few details. The host country is a former imperial colony and many of the researchers and funding institutions are from the former colonizing country. Research participation is not mandatory to receive medical care at the clinic. Finally, no other medical sites exist within reasonable walking or driving distance. The medical facility is a core part of the research project, and due to cross-use of the medical equipment, the two cannot be separated easily.

Further information that would be relevant to the ethics of the case is:

- Aims and desired impacts of the study/studies and what the exact parameters of those studies are.
- Types of data collected at the field site (e.g., biological material, or measurements).
- Length of studies (e.g., some studies are very long term or multi-generational).
- Degree of invasiveness of the data collection, either in impact or procedures.
- Risks versus benefits to participants.
- Description of relationships between the field site/medical facility and the local residents (good, tolerable, [mis]trustful, tenuous, etc.).
- Research protocols used to explain voluntary, non-obligatory participation.
- Participant recruitment protocols.
- How many local employees at the site are also research participants.

- Researcher backgrounds: Rank (senior or junior faculty, graduate students), affiliations, experience.
- Funding institution(s).

All these aspects are useful to think about or to know because they give better picture of the nuanced ways in which people interact on this project and their motivations.

Contemplate: Prioritize information and identify ethical dimensions

- What facts are particularly crucial?
- What ethical principles apply to the case?
- What values are in conflict?
- Are there any underlying issues or hidden agendas?
- What social structures have contributed to the dilemma?
- What are the benefits or burdens of the available options?
- How does this case compare to others you have experienced or heard of?

This scenario seems to emphasize issues of free consent. The crucial ethical points are whether local residents feel obligated to participate in the study for any reason, including employment or medical services.

The scenario's dilemma might arise due to motivations that could be in conflict with free consent like the incentives of the researchers, such as addressing certain research questions, publishing, progressing towards a degree or a promotion. There are social structures that also contribute to the scenario's dilemma. Poverty and inequality of resource access in the local population possibly stems from the lack of job opportunities in the area. The rural area where the site is located contributes to the lack of job opportunities. Therefore, the medical facility providing care and jobs is a valuable resource. Additionally, the dynamic between colonizer/colonized is influential between researchers and participants, even if no longer explicit.

Evaluate: Analyze options and justify recommendations

Now that I have thought through multiple dimensions of the scenario, I will work through the best possible options to the researchers at the field site.

- Option 1
Keep everything at the field site as it is in the scenario. The benefit would be maintaining high study participation, employment, and access to healthcare, but the possibility of lack of free consent to participate in the study would remain.
- Option 2
Not employ local residents at the field site so that there is no obligation to participate felt by the local residents to their employer. This option could possibly reduce pressures to participate by employees, but it would present multiple negatives as well. The loss of jobs in an area without many alternative economic opportunities would be detrimental to the individual and their families. Also, just because the residents are not employees does not mean that there would be fewer obligations felt if they are asked to participate in research. The facility is the only medical center in the area.

- A better version of this option would be that the local residents are employed by the medical center and can participate in research, but no local residents may be employed as recruiters or consenters. This may prevent some pressure exerted to participate but it does not alleviate any of the education, economic, or former colonizer/colonized power dynamics that could still be in play between consenters or recruiters and potential participants.
- Option 3
 - Separate the field site and the medical facility so that they are independent in staff and operation. This separation would be beneficial because medical care and jobs would still be available, but by having less direct ties to the medical center and employment the participants may feel less pressure to participate in research. However, without the medical facility connection, the field site must purchase and transport all the required medical equipment. The cost of new equipment may be prohibitive which could prevent the study from occurring or slow its progress. Additionally, integrating medicine and research is supported over strictly separating them by some models such as the Institute of Medicine's "Learning Healthcare System" (<http://www.learninghealthcareproject.org/section/background/learning-healthcare-system>).

While someone else may interpret this situation differently, these are three options that seem to be viable possibilities during my critical reflection on this scenario through the RICE guide. These are probably not the only options. My own research does not deal in biomedical or human biology fieldwork like that described in the scenario, so my lack of specific experience may mean that there are avenues I have not thought of.

My instinct would be to recommend the first option outlined above: to keep the system as described. The path seems to provide the most benefits with the fewest negative impacts either to the local residents or the research site. However, I would recommend that the researchers make efforts beyond normal informed consent procedure to explain that anyone receiving medical care has no obligation to participate in research. These efforts may include things like conducting local surveys and using or training local researchers.

* Whiteford, LM and Trotter, RT (2008). *Ethics for Anthropological Research and Practice*. Long Grove, IL: Waveland Press. (p.113)