



## Informed consent among analog people in a digital world<sup>☆</sup>

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### ABSTRACT

This paper addresses the concept of informed consent when working with remote, non-literate groups. By examining both the legal and moral obligations of informed consent, it will be argued that “erring on the side of caution”, for instance by not publishing on the Internet because the consultants/community do not have exposure to such things, is just as paternalistic as assuming that they would consent if they understood. It is further argued that the researcher has an obligation to explain the research to the consultants/community as fully as possible and to engage in an ongoing negotiation of consent, but that the researcher must respect the autonomy of the consultant/community decision, even if the consent was not fully “informed”.

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### 1. Introduction

Often, when fieldworkers think of the phrase “informed consent”, it is with irritation. The phrase calls to mind the ethics review processes of the Institutional Review Board (IRB) that many linguists and anthropologists dread. They lament that the IRB (or similar ethics review board for researchers based outside the US) does not understand social science research, let alone the realities of fieldwork in remote areas, where obtaining consent in writing may be counterproductive or even impossible. This paper will address some of the thornier issues involved in obtaining informed consent, focusing especially on the perspective of field linguists working with remote non-literate populations in the third world.

Ensuring that consultants and collaborators understand our research is not always straight-forward. As academics, we often have a hard time making ourselves understood to lay people in our own communities (*What is it that linguists do anyway?*), and this problem is augmented by the difficulties of cross-cultural communication and language barriers, especially when dealing with a non-literate, remote community. Can a consultant or collaborator give informed consent to a language documentation program involving audio and video recording, archiving and dissemination on the web when they have never even seen a computer? According to the definitions of “informed consent” that most IRBs adhere to, the answer is no. People cannot consent to something they do not understand. Does this mean that we should not do research with such isolated ethnolinguistic groups? Is it paternalistic to say that such individuals, who are of sound mind and legal age, cannot give their consent to language documentation projects? Is it more paternalistic to say that we believe that they would consent if they understood?

These questions will be explored in this paper, which will make reference to the author’s fieldwork among a hunter-gatherer group in the Philippines. Unlike many American Indian and Australian groups, the Dupanangan Agta ethnolinguistic group does not see their language as sacred and has no qualms with making information about their language public. They enjoy being photographed and video recorded and are excited about the prospect of making such materials public. Can I take that as consent, even though I was never able to adequately explain that the materials would be available through an archive?

<sup>☆</sup> The title of this paper was somewhat troubling, as it seemed patronizing to call a people “analog”, but, in keeping with the conclusions of the paper, I decided that being true to the situation is more important than an arbitrary aversion to paternalism.

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In the following sections of this paper, I will address both the legal and moral obligations of informed consent, including the legal obligation to obtain consent in writing, how to obtain oral consent, the problems raised by sacred or secret linguistic materials, obtaining informed consent for open-ended research, obtaining informed consent for that which the consultants/community have no experience (such as the Internet), paternalism, vulnerable classes, and autonomy. It will be argued that “erring on the side of caution”, for instance by not publishing on the Internet because the consultants/community do not have exposure to such things (and thus could not possibly consent to them), is just as paternalistic assuming they would consent if they understood. It will be further argued that the researcher has an obligation to explain the research to the consultants/community as fully as possible and to engage in an ongoing negotiation of consent, but that the researcher must respect the autonomy of the consultant/community decision, even if the consent was not fully “informed”.

## 2. The research background

The ethical dilemmas described here are informed by the author’s field experiences in the northern Philippines, living with a group of semi-nomadic foragers for a year while writing a descriptive grammar of their language (Robinson, 2008). Dupanigan Agta is a threatened language; while there are some children who no longer command the language, most children do. On the other hand, borrowing and code-switching are rampant, and many children who are capable of speaking Dupanigan Agta nevertheless do not respond to their parents in the language, preferring instead the trade language, Ilokano. All of these are signs which suggest that language shift could be imminent. There are about 1400 speakers of the language in some 35 communities scattered across approximately 3000 square miles along the northeastern coast of Luzon Island, Philippines. The Dupanigan Agta are members of the Negrito ethnic and racial minority, which consists of some 33,000 people throughout the Philippines (Headland, 2003) as compared to a total population of approximately 90 million in the country. Negritos, including the Dupanigan Agta, are often discriminated against in terms of health care, jobs, land titles, and other basic human rights. The Dupanigan have a subsistence economy based on fishing, gathering, horticulture, and hunting, and they often move camps for reasons of both subsistence and interpersonal relations. The camps where the Dupanigan Agta live lack basic infrastructure, such as roads, electricity, and running water. Very few Dupanigan Agta go to school, and the majority is illiterate.

Crucially for the question here, the Dupanigan Agta and other Negrito groups have been very friendly and receptive to outsider-researchers. They welcomed me into their community and were disappointed when I left. They consented to the research and to being recorded, although I believe many never fully understood my research and most were not interested in the research, *per se*. They did not realize that their language was endangered (I was only able to convince one person of the seriousness of the situation), and language issues, in general, were of low priority, especially as questions of land and of subsistence were quite pressing. The community as a whole, though, was quite interested in my presence, as I brought both prestige and wealth.

Due to barriers of language and background, I generally gave quite simple descriptions of my research. I said that I was interested in their language, and that I was going to write a dictionary. My actual research was a grammar, dictionary, and texts, but most Dupanigan people would not have had familiarity with the concept of a descriptive grammar, so I chose to frame the project as a dictionary, since this was a concept that most individuals would have been familiar with. After explaining the project in those simple terms, I explained my present purpose to that individual (e.g., I would like to have you translate some words so I can see how your vocabulary is different from Dupanigan speakers in other areas, or I would like you to tell a story, etc.). Next, I would explain that I was recording them (luckily, a concept familiar to most Dupanigan Agta), and finally, I would ask if it was all right to “share the recording with my companions”. They always consented to this, and were generally uninterested in the consent process.

I did not go into specifics about how the data would be disseminated (e.g., on the Internet) or stored (in an archive), although, in retrospect, I probably should have. I wish I had been more explicit about dissemination, asking, for example,

Who would be allowed to see this material?:

- nobody
- only you
- only a subset of the community
- only the community; only the community, the researcher, and the researcher’s colleagues
- everyone

I also did not use written consent forms, and I did not read aloud the consent form approved by the IRB at my institution, as I believe this would have been a hindrance to true understanding and thus would have violated the spirit of the consent process.

With long-term consultants, I also explained that they would be paid, and I discussed with them what the longer-term commitment entailed. I then negotiated with such individuals about how the research would be scheduled and allowed them to negotiate for additional payment schemes. My primary consultant and I agreed, for example, that I was also responsible for ensuring that his family would not go hungry and that I would buy a water buffalo upon leaving the community (both obligations which I lived up to).

I never encountered any taboos on any part of the language, and I was never told that anything should remain secret or restricted. In contrast, the Dupanigan Agta were generally excited to be photographed, and video and audio-recorded. The adult

nephew of my primary consultant even commented jealously that his uncle was becoming a “star”. The Dupaningan Agta have no exposure to the Internet, having only seen my computer, which did not have Internet access in their camp, but they do understand and occasionally use cell phones and text messages. It is in this light that the following comments should be understood.

### 3. Informed consent: legal requirements

In the latter half of the 20th century, courts and governments around the world began to regulate research involving human subjects, especially after the Nuremberg trials of Nazi doctors who conducted wildly unethical medical experiments during World War II. The resulting Nuremberg code called for voluntary consent by participants, among other protections. In 1964, the World Medical Association issued a follow-up declaration, known as the Declaration of Helsinki, and a revised form of the declaration is still considered a worldwide standard for biomedical research involving human subjects. In the United States, during the 1960s, the National Institute of Health began requiring that any research conducted with its government funds be subject to ethical review. Each institution was responsible for internal review of its own research protocols if they were to receive this federal funding. Thus, Institutional Review Boards (IRBs) were born at research institutions across the country to review research protocols. This mandate was subsequently expanded to cover all research at institutions that received any federal research funding, and today, virtually every research institution in the United States has an IRB composed of various researchers who review every research protocol involving human subjects (Berg et al., 2001). The IRBs judge the protocols against the current federal standards developed by the department of Health and Human Services, which include informed consent. Many other countries have similar ethics review boards, but the rules and regulations vary, and in some countries, only biomedical research is covered. The comments that follow are specific to the United States but should be relevant to other countries with similar review boards.

As can be seen from the above discussion, the current US regulations were developed with biomedical research in mind (Plattner, 2003, p. 292), but social science researchers, including field linguists, are also required to submit their research protocols to IRBs. Although most field linguistics is considered “exempt” (meaning it is exempt from ongoing review after passing a first review), it must still pass an initial limited review process, and it is because of experience with this process that many investigators have negative attitudes towards the IRBs at their institutions.

One of the most common hurdles faced by linguists in getting IRB approval for their projects is the question of writing. Many IRBs insist that informed consent be in writing, which is particularly problematic when working with non-literate populations, but also poses problems in field situations where people tend to mistrust forms and contracts. The current US regulations state that informed consent shall be in writing unless “the research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside of the research context.” (Protection of Human Subjects, 2005, Section 46.117) These regulations contain no specific provision for obtaining informed consent orally. That is, informed consent is either required in writing, or it is not required at all. While most Westerners would consider linguistic research to involve “minimal risk of harm” (but see further discussion on this topic below), IRBs have generally erred on the side of caution and required consent in any case. But a partial answer can be found in the Declaration of Helsinki (World Medical Association, 1964 [revised 2008], B.24), which states that “[i]f the consent cannot be expressed in writing, the non-written consent must be formally documented and witnessed.” So there is a provision in international law allowing for oral consent, and anecdotally, it seems that most linguists working with non-literate populations have been able to convince IRBs that oral consent is necessary (although the problem of literate populations who are mistrustful of forms by and large remains). In my research with the Dupaningan Agta, the IRB at the University of Hawai‘i required a written consent form to be drawn up in a local language, but conceded that oral consent would suffice for non-literate individuals.

So, if we are allowed to obtain oral consent, how can we show that we are still complying with informed consent guidelines? Many linguists today are using oral scripts or checklists. Scripts are potentially problematic, however, because they can be written in such a way that they are difficult to comprehend, and even if they are written in straight-forward language, the mere act of reading a text aloud can hinder comprehension. I advocate, therefore, the use of checklists. A checklist must include all the same information as a written consent form. Namely, discussion of the purpose of the research, of the type and duration of research procedures, of risks and benefits, of confidentiality (if any), the contact information of responsible individuals, and a statement that research is voluntary (see Bower, 2008 for a sample checklist). IRBs may vary on their permissiveness in allowing such lists.

### 4. Informed consent: moral requirements

But “informed consent” is not just a legal process, it is also a moral one. Although we may tell the IRBs that our research involves “minimal risk of harm”, and by Western standards, this is certainly true, in many other cultures, linguistic research is potentially quite dangerous. This can be because we record potentially incriminating or embarrassing material (see Dorian, this issue), but more detrimentally, because we record sacred or secret material. This could be a certain secret language, a genre of myths (see Innes, this issue), or even the entire language (see Debenport, this issue). By truly international standards, then, we have an obligation to pay close attention to the ways in which linguistic research can be harmful.

Thus reframed, we can see that linguistic research is potentially quite harmful and so requires our heightened awareness. Two big problems arise in this regard. First, language documentation is, by nature, open-ended (Himmelman, 1998). The

research is open-ended in that what questions we ask tomorrow are informed by our analysis of what we learned today. Moreover, the research *outcomes* are open-ended. We seek to create a long-lasting, comprehensive record of the language or variety in question, and we want that record, or corpus, to be available for future researchers. It is thus not only theoretically impossible to obtain consent for all future research and research outcomes, but also undesirable. That is, we do not want to restrict our research process or future uses of the material simply because we cannot guess today what those will be.

Second, when working with remote populations, it may be difficult to obtain *informed* consent to make the data accessible in ways that are not familiar to the community or consultants (see Dorian, this issue, on how this may be problematic even in first world situations). For example, it is now the standard in language documentation to archive one's materials for safe-keeping (see e.g., Austin and Grenoble, 2007) and to disseminate them as broadly as possible. The broadest way to disseminate materials is via the Internet. But how can we obtain truly *informed* consent for these things if the consultant and the community have never seen a computer or heard of an archive or the Internet? Bownen (2008, pp. 180–181) asserts that “[i]nformed consent is meaningless if the person does not know what they are agreeing to. For example, a person agreeing to put materials on the internet has not given informed consent if they do not have access to a computer and have never used the internet.” Does that mean that linguistic materials from the Dupaningan Agta and other remote, non-literate communities can never be posted on the Internet? To push the question further, would the linguist be prohibited from publishing the materials in print if a hypothetical group had never seen a book?

Both with open-ended research and with publishing on the Internet, the answer seems to be that we do our best to explain what we can now, and in the future, if we are unable to contact the community, we must make decisions based on our earlier discussions. But as Dwyer (2006, p. 32) notes, “[a]ssumptions about what is ethical for a particular field situation are best avoided, especially assumptions on the part of the researcher about what participants want.” How, then, can the well-intentioned, ethical researcher deal with these two issues? Interestingly, linguists seem to have taken opposite approaches to the two questions. With regard to open-ended research, we seem happy to allow future uses of materials for which consultants and communities have agreed to allow access. With regard to publication on the Internet, linguists have tended to err on the side of caution and not publish on the Internet without explicit permission. But I would argue that erring on the side of “caution” and not publishing on the Internet is just a paternalistic as deciding that the community would approve if only they understood. I spent a year in the field working with the Dupaningan Agta to produce a grammar, dictionary, and texts of their language. They agreed to have this research disseminated and indeed were pleased that others would learn (about) their language. Is it not, then, a moral obligation to disseminate the information as widely as possible?<sup>1</sup> We are thus in an ethical bind. To decide to publish something on the Internet when the consultants do not understand the Internet is to make a decision on their behalf. But to not publish on the Internet is also making a decision on their behalf.

## 5. Vulnerable classes

Are the Dupaningan Agta and other remote, non-literate groups especially vulnerable to exploitation? Given the history of colonial exploitation throughout the world, the answer seems a resounding yes. With regard to informed consent, the current US federal regulations state that “[W]hen some or all of the subjects are likely to be vulnerable to coercion or undue influence, such as children, prisoners, pregnant women, mentally disabled persons, or *economically or educationally disadvantaged persons*, additional safeguards have been included in the study to protect the rights and welfare of these subjects.” (Protection of Human Subjects, 2005, Section 46.111, emphasis added). Any non-literate person or group would certainly be considered educationally disadvantaged, but to include them as incompetent with children and the mentally disabled is especially unpalatable. They are adults of sound mind who seem competent to make their own decisions. Legally, however, competence is defined as being able to understand the information disclosed in the consent process, so “a patient who does not know or comprehend the requisite elements of disclosure could be considered incompetent” (Berg et al., 2001, p. 101). But problematically, a high standard of understanding would mean that many if not most people would be ruled incompetent. After all, most literate, educated Western non-linguists do not understand linguistic research, and Dorian (this issue) points out that academic research and publications are very unfamiliar even to those who have experience with other types of publications.

## 6. Autonomy

To resolve this dilemma, we return to the legal notion of informed consent. Informed consent is “rooted in our society's cherished value of autonomy” (Berg et al., 2001, p. 3). While Berg et al. are referring to Western values, and they acknowledge that informed consent thus runs into problems when applied elsewhere, I argue that the notion of autonomy is important in these cases too (but see Dobrin, 2008 on how focusing on autonomy can be ethically problematic cross-culturally). The researcher has an obligation to explain the research and the research outcomes as fully as possible “in language understandable to the subject” (Protection of Human Subjects, 2005, Section 46.116). One way to accomplish this is through use of

<sup>1</sup> I have indeed posted the descriptive work on the Internet, and although the documentary corpus is too large for my current capacity, I would like to make the entire corpus available on the Internet.

analogy, but however the researcher attempts to explain these concepts, understanding may fail. It is important to note, however, that this is not unique to working with remote, non-literate populations. Studies have shown that medical patients in Western settings often do not fully understand the treatment they have consented to (Berg et al., 2001, p. 102).

Legally, there is no generally agreed upon standard of understanding for informed consent within US medical contexts (Berg et al., 2001, p. 66). The federal regulations focus instead on the researcher or doctor's obligation to disclose information in a way that could be potentially understood by the patient. This may seem problematic. Are we really absolved of our duty if we explain our research, even if we know that the consultant or community did not understand? Don't we have a moral obligation to ensure that our consultants understand? Here is where we return to the question of autonomy. The problem is that if we focus on understanding over disclosure it could mean that subjects who did not understand were denied the autonomy to make decisions (Berg et al., 2001, p. 152). In this regard, the 1978 Belmont report, which is the precursor to the current US regulations, states that even in cases of incompetence, the wishes of the subject should be considered as much as possible (Berg et al., 2001, p. 256).

This does not mean that we should make an attempt to explain and then consider our moral obligation absolved. The process of consent should be ongoing (see, e.g., Miller and Bell, 2002; Thompson, 2002). While we must explain our research at the outset, we do not need to explain every single aspect of it on the first day (especially when we are engaging in a long-term, open-ended, multi-faceted research project). We should explain the crucial parts at the beginning, other aspects as appropriate, and continue to negotiate research outcomes and publication at various intervals. It is very different to consent to making everything public at the outset when the research outcomes are still vague as opposed to consenting afterwards when the consultant/community has an idea of the materials in question.

## 7. Conclusions

Therefore, I argue that we have a moral obligation to explain our research as best we can, obtain consent in an ongoing and collaborative way, and then do our best to respect those decisions, whether or not we believe them to be truly informed. I further argue that a certain amount of decision-making by the researcher on behalf of the consultant/community is not unwarranted. We must use our knowledge as participant observers, as speakers of the language (albeit non-native or partial speakers), and as adopted members of the community to make ethical decisions about our research outcomes. The inability to explain the linguistic side of our research does not trouble us, and the inability to explain research outcomes and methods of dissemination should not prevent the research and dissemination from taking place. Although we may train some individuals about linguistics, we generally do not consider it problematic if we work with individuals who do not understand what a relative clause is. We thus acknowledge that the consultant/community do not need to have full understanding of our research and research outcomes. I argue, then, that if the consultants do not need to understand relative clauses to consent to the writing of a descriptive grammar, then they do not need to understand the Internet or an archive to consent to these things, either. In fact, by simply asking who would be allowed to see a particular resource, we can allow the consultant to have the autonomy to make the decision even in the absence of full understanding. If the consultant/community agrees that everyone could be allowed to see a particular resource, then making it available on the Internet should not be problematic. Moreover, if we do bring our laptops into the field, a mock-up of the expected Internet presentation could go a long way to bridging the gulf of understanding.<sup>2</sup>

Of course, as many authors have noted, there is no single solution when dealing with ethical issues (see e.g., Rice, 2006; Thieberger and Musgrave, 2007; Dwyer, 2006). What works in one case may not work in another. The situation discussed here is a very specific one. It is that of an outsider, Western researcher or research team doing a language documentation project with a group of non-literate, remote peoples who generally have few restrictions on how their language data may be used. This clearly does not pertain to all linguistic fieldwork situations.

Much recent work on ethics in linguistics has focused on work in the "empowerment model" whereby the community is actively engaged in designing the research (Cameron et al., 1992). Moreover, much of the work focuses on research the US, Australia, and Canada (but see Dobrin, 2008) where sacred language is more common and histories of colonialism have led to an understandable hyper-vigilance on the part of communities. Many of us who work in other parts of the world have sat back and watched the debate, thinking smugly to ourselves that the ethical issues where we work are not so tricky. The language is not considered sacred, and the community is happy to let us go about our business on our own. But as I hope I have shown, research in such settings is not without ethical dilemmas. We are not "exempt" from the ethical imperative to do right by our consultants (Fluehr-Lobban, 1994).

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