Informed consent among analog people in a digital world

Laura C. Robinson
Rice University
International Conference on Language Documentation and Conservation
Honolulu, Hawai‘i, March 12-14, 2009
laura.c.robinson@rice.edu

Questions
- What is “informed consent”?
- How can linguists work with IRBs to create a meaningful consent process?
- How can linguists work with remote, non-literate communities to negotiate a meaningful consent?
- Can someone who’s never heard of the Internet consent to having language materials posted?

The research background
- This research is coming from the perspective of an outsider linguist working with a remote, non-literate community
- This research is based on a year of fieldwork in the northern Philippines
- The Dupaningan Agta are semi-nomadic foragers
- They are members of the Negrito ethnic and racial minority
- The language is threatened
- They lack basic infrastructure and education
- They are generally open to outsider researchers
- There are no known secret or sacred domains
- Open to audio/video recording
- Excited about dissemination of research
- Uninterested in consent process

Linguists and the IRB
- If linguists approach the IRB process with respect, they are likely to have a better experience
- The IRB process could be considered an opportunity to think through the ethical issues involved with fieldwork

Informed consent: Legal considerations
- Obtaining consent in writing is problematic if community is not literate or is mistrustful of forms
- 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.” (§46.117)

- That is, informed consent is either required in writing, or it is not required at all.

---

1 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.

2 I would like to thank the members of my seminar in language documentation in the Spring of 2009 at Rice University for sharing their thoughts on the subject matter of this paper. This does not mean, of course, that they necessarily agree with me.
But we need to obtain consent and most IRBs will want us to anyway.

The Declaration of Helsinki, first created in 1964 and currently an international standard for ethics in medical research states that

“If the consent cannot be expressed in writing, the non-written consent must be formally documented and witnessed.”

Many linguists today are using oral scripts or checklists.

Scripts are potentially problematic because they can be difficult to comprehend.

Checklists ensure that reader and consultant are communication.

A checklist must include all the same information as a written consent form.
- purpose of the research
- type and duration of research procedures
- risks and benefits
- confidentiality (if any)
- contact information of responsible individuals
- statement that research is voluntary

**Informed Consent: Moral considerations**

- Cross-culturally, we find that linguistic research may involve much more than “minimal risk”
- Research processes in language documentation are open-ended and thus obtaining truly “informed” consent at the outset is problematic
- Language documenters want to make primary data available for future generations, and thus it is impossible to predict how the data will be used, making “informed” consent problematic
- Language documenters want to disseminate the data widely, but remote, non-literate communities may not have experience with archives or the Internet, making “informed” consent problematic

> “Informed 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 don’t have access to a computer and have never used the internet.” (Bowern 2008: 180-1)

Researchers want to avoid making paternalistic decisions for communities

> “Assumptions about what is ethical for a particular field situation are best avoided, especially assumptions on the part of the researcher about what participants want.” (Dwyer 2006: 32)

Should we err on the side of caution, for example, by not publishing on the Internet?³

But in so attempting to avoid paternalism, we are being paternalistic by deciding *not* to publish

We can make the consent process more productive by using analogies or by asking *who* could be allowed to see certain materials.⁴

We must respect the autonomy of our consultants to make decisions, even when they don’t fully understand

---

³ I have indeed posted my descriptive work on Dupaningan Agta on my website (http://www.owlnet.rice.edu/~lcr3/), and although the documentary corpus is too large for my current capacity, I have plans to make the entire corpus available on the Internet.

⁴ The question could be framed: “Who would be allowed to see this? nobody; only you; only a subset of the community; only the community; only the community, the researcher, and the researcher’s colleagues; everyone.
Conclusion

- We should explain ourselves the best we can
- We should engage in an ongoing collaborative consent process
- We should respect the autonomous decisions of consultants
- However, ethics statements are not always generalizable
- This talk represents the perspective of the outsider linguist working with a non-literate community
- Much of the work on linguistic fieldwork ethics has focused on the US, Australia, and Canada, (but see Dobrin 2008) and it is hoped that this research can broaden the focus of discussion

Works cited