Navigating the Ethics of Human Subjects Research

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About two years ago, I was in the field interviewing members of several indigenous groups in Central America. I was evaluating a past foreign aid project funded by a multilateral bank and implemented in their territory by a local graduate school, focusing on the political dynamics between funders, implementers, and community members. While I anticipated finding potentially contentious relationships, I did not anticipate the ethical concerns interviewees expressed about the professors and graduate students who implemented the project.

As attentive as I have always been to human subjects concerns, their narratives were still a wake-up call: indigenous leaders made clear that the only benefit of that project was the many papers, publications, and conferences that the implementers had produced from knowledge gained while in the territory. Locals felt like their ancestral knowledge had been tested and commoditized in the form of CV lines and researcher travel funds, and then published behind paywalls where they could not reach. Little evidence of that project remained fifteen years later. One of the community leaders refused to ever work again with the graduate school, even knowing it would limit their chances to obtain external grants from multilateral organizations reserved for indigenous issues.

But in that moment, I was also in their community as a researcher – was I any different? Would my research genuinely benefit them, or was I collecting their experiences for a line in my CV? Human rights and Adivasi activist Dr. Abhay Xaxa, a sociologist by training, asserts a powerful response to these questions for all researchers to reflect on. "I am not your data" was written to lambast the Indian government's treatment of the Adivasi – the collective term for indigenous groups in India – as nothing more than data and numbers:

> *I am not your data, nor am I your vote bank,*
> *I am not your project, or any exotic museum object,*
> *I am not the soul waiting to be harvested,*
> *Nor am I the lab where your theories are tested,*
> *I am not your cannon fodder, or the invisible worker,*
> *or your entertainment at India habitat center,*
> *I am not your field, your crowd, your history,*
> *your help, your guilt, medallions of your victory,*
> *I refuse, reject, resist your labels,*
> *your judgments, documents, definitions,*

your models, leaders and patrons,
because they deny me my existence, my vision, my space,
your words, maps, figures, indicators,
they all create illusions and put you on pedestal,
from where you look down upon me,
So I draw my own picture, and invent my own grammar,
I make my own tools to fight my own battle,
For me, my people, my world, and my Adivasi self!
- Abhay Xaxa (2016)

Xaxa demands we reflect on the fine line between research and exploitation, a line rarely talked about in international relations (IR) research. In my own case, I had of course carefully filled out an Institutional Review Board (IRB) application in the U.S. for formal ethical approval to work with these groups long before my arrival, but in no way was my dilemma covered – nor is IRB review or that of equivalent bodies meant to be a blanket ethics approval for working with informants. Filling out an ethics board application may be the first time that a researcher thinks about protecting their future informants, but the ethics of working with those individuals go far beyond a standard application. Even the commonly used phrase "human subjects" on these applications allows us to keep our informants at arm's length, invoking the idea of a data source that is more object than person. As IR scholars, we know that global systems are complex and that there are multiple and indirect consequences for every action taken. Beyond exploiting their knowledge, could your research get one of your informants deported? Thrown in jail? Separate a family? Get someone fired? Take away future jobs or income streams? Take away land rights? The list goes on.

Unlike medical experts, there is no oath social scientists take to 'do no harm.' Nevertheless, the scientific method purports to rigorously analyze systems *without* changing the system. Paying careful attention to ethics is necessary to fulfill this charge. While it is impossible to ignore the researcher's positionality and resulting influence when working with human subjects – an issue I will discuss in this chapter – the idea is to minimize the researcher's effect as much as possible during the research process. This is not related to the debate on whether research can have an activist aim; activist research is in no way precluded from being ethical. It simply means that the research itself should shed light on the systems in question while maintaining the confidentiality of the specific people who allow you to empirically demonstrate your hypotheses.

Your project becomes subject to federal regulations if it meets the legal definition of human subjects research in your country, whether you realize it or not. This definition is generally divided into two parts in each country context: what types of **human subjects** data counts**,** and what counts as **research**. In the U.S., for example, all work with people is subject to the Federal Policy for Protection of Human Research Subjects, known as The Common Rule.[1] There, a "human subject" is defined as (emphasis added to highlight typical IR research):

> *"a living individual about whom an investigator (whether professional or student) conducting research:*
> *(i) Obtains information or biospecimens <u>through intervention or interaction with the individual</u>, and uses, studies, or analyzes the information or biospecimens; or*

[1] See Health and Human Services regulation 45 CFR Part 46: https://www.hhs.gov/ohrp/regulations-and-policy/regulations/common-rule/index.html

(ii) Obtains, uses, studies, analyzes, or generates identifiable private information or identifiable biospecimens."[2]

Thus, if you perform experiments, surveys, interviews, focus groups, field observations, or even use pre-existing data sets with identifiable information, your research fits the legal definition of human subjects data in the U.S., and most likely in many countries/territories. Additionally, most peer reviewed publications require proof of an ethics board approval before they will publish your work.

Although data collected for program evaluation or program management purposes is generally excluded from the definition of **research** for human subjects purposes, monitoring and evaluation research still fall under the standard definition of research if the data analyzed is meant to contribute to *generalizable knowledge*. Essentially if you are trying to take lessons learned from the data and make recommendations to others beyond your population of study, or publish your evaluation findings, you still fit the legal definition of *human subjects research*. It can be a difficult distinction to make,[3] and often best made in concert with an ethics board.[4]

Nevertheless, even if your project does not require formal approval from an ethics body like the IRB, any data collection in any project involving people should always be undertaken by researchers in an ethical way that respects and protects the lives of your respondents. And as evidenced in my own example working with Central American indigenous groups where approval was required, ethics oversight boards do not address every aspect of ethical research conduct in their applications to which researchers should still be attentive.

So, what are the main ethical concerns and how do we navigate them? This chapter is meant to both guide researchers to answer these two questions but also encourage further reflection on them in the context of your studies. In **Part I**, I will identify some of the **main ethical concerns** when working with informants. In **Part II**, I will discuss how to address these concerns during the **research design process**, including choosing your method, instruments, country case, and sample. This will include an integrated discussion on including safeguards to avoid exploiting your participants. In **Part III,** I will give guidance on **navigating formal ethics approval processes**, including planning your recruitment strategy and how to assess risks, and determine any additional ethics requirements you are subject to in other countries and indigenous lands. In **Part IV**, I will discuss **ethics in the field**, such as recruitment, how to think through the issue of researcher positionality, exceptions to confidentiality, and the ethics of website/social media posts about your research. Lastly, in **Part V**, I will discuss some final reminders when **describing your results** to reinforce informant protections.

Part I – Main Ethical Concerns

When discussing ethics, much emphasis is usually put on confidentiality: what is it? While formal ethics approval processes aim to make sure that all participation is informed and voluntary, what other ethical issues should we be concerned about when designing IR research? Ethics is not a subject IR researchers-

[2] See Health and Human Services regulation 45 CFR Part §46.102: https://www.ecfr.gov/cgi-bin/retrieveECFR?gp=&SID=83cd09e1c0f5c6937cd9d7513160fc3f&pitd=20180719&n=pt45.1.46&r=PART&ty=HTML#se45.1.46_1102

[3] For a helpful discussion on the differences, see the University of Conneticut's human subjects research resources: https://ovpr.uconn.edu/services/rics/irb/researcher-guide/does-evaluation-require-irb-review/

[4] For a current list of U.S. IRBs in good standing, see: https://www.aahrpp.org/learn/find-an-accredited-organization

in-training typically spend much time on, but its importance in protecting the lives of research participants cannot be stressed enough. It is easy to leave their lives in disarray long after your project ends. Here I have identified four major concerns and sample consequences to consider when it comes to navigating the ethics of human subjects research: confidentiality, harm, exploitation, and data integrity.

Confidentiality

Confidentiality is when the researcher knows the identity of the participant but keeps it concealed, while anonymity refers to situations when even the researcher does not know the identity of the participant. Most IR studies fall into the former category. No matter your field or type of informant, research involving human subjects can have serious consequences if confidentiality is not maintained. For example:

- Interviewing the town mayor about a foreign aid project and publicizing their unfavorable views on the project may mean that town will not be chosen in the future for a separate project, cutting off an income source for the community.
- The opinions of a person hired to implement a project could cost them their current or future job if their employers do not agree with them.
- Quoting elites by name without their consent could lead to them being reassigned or fired.
- If your research is about skirting a particular law and your informants confirm your theory, it could lead to jail or other serious legal consequences for them, such as deportation for undocumented immigrants or the destruction of homes in informal settlements.
- Revealing the location of rape victims, or victims of political violence, or the headquarters of a resistance group could easily alert their abusers or opponents to their whereabouts and put them in physical danger.
- Audiotaping the interview and leaving the file on an unlocked phone or recording device before removing identifying information will reveal your sources to anyone using that device if stolen or hacked. This is especially worrisome in the case of research on sensitive topics or in conflict environments, where opponents may specifically attempt to obtain the data collected.

To further illustrate the potential consequences of protecting confidentiality, I met a documentarian at a student event who made a film on sexual violence in Central America a few years ago. Rates of abuse and femicides in the filming location were sky high. Local women had to fight back against both their abusers and the political and legal systems that privileged the abuse, and as such were high value targets by their opponents. They had taken a big risk participating in the documentary in the first place. When word got around about the film project in the community, the documentarian herself was subject to a break-in of her rental lodgings one night, was raped, and some of the unedited footage already filmed was stolen from her lodging to obtain the identities of these individuals and attempt to silence all parties speaking on this issue. While criminal activity against subjects and researchers is in no way their fault, I use this example to point out the situations researchers can face in the field to illustrate the real-world importance of research ethics.

Harm

Harm can come in physical, emotional, financial, or any other form to informants. Confidentiality breaches clearly can go hand-in-hand with potential harm to the participant, as in the sexual abuse documentary example. But there are additional ways that participants can be physically and emotionally harmed during the research process, even without the researcher revealing their identity in any papers or presentations. For example:

- When participation is not voluntary. While it may not be the researcher forcing participation, it may be an employer, family member, political figure, etc., coercing the participant with the threat of negative repercussions for non-participation.
- When participants are not properly informed about the risks of participating in the study. This harm could due to an incomplete, misleading, or all together lack of an informed consent process, or because the participant has difficulty understanding the vocabulary or language used by the researcher in the consent process.
- In fragile contexts, you can exacerbate conflicts. Your very presence in the field will inevitably have an influence, but could have dangerous consequences in environments where there is war, violence, and/or political instability if you are not attentive to the context.
- Using false information in an experiment to analyze how a participant reacts. It could traumatize individuals who do not know it is false, and/or come from environments where factual information is hard to access.
- Being unclear up front about whether participants will be compensated. If someone expects compensation when there was none and took time off of paid hourly work to participate, they will lose income that day.
- Paying your informants without knowing about cultural norms and hierarchies. Payment may make that informant vulnerable to robberies or other forms of retribution if not deemed as an appropriate participant/breaking a hierarchical structure per local norms.
- Similarly, being seen with an informant by other community members who feel they have been left out of your research. This could bring on other negative social consequences for your participant.

Some studies may indeed have potentially harmful effects that cannot be avoided, for example asking people to recall painful experiences may trigger mental health concerns, or seeking out opposition leaders to interview in conflict environments could expose them to potential harm from political enemies. As we will discuss in this chapter, it is critical to ensure that participation is voluntary and informed in these situations, so that individuals can make an educated decision about whether to continue with the research.

Exploitation

As highlighted in the introduction to this chapter, there is a fine line between research that serves a population by helping us better understand some phenomenon – the purported benefit of participation listed in most informed consents – and the exploitation of individuals in its pursuit. Your informants are not likely to believe that your research will reap any real benefits to them in the long run if there is no policy goal and future results are only accessible at a cost. This is especially true if working with vulnerable populations. In the worst case scenario, they may feel their private lives and livelihoods have been put on the line and made public to help solve a research problem they may not even think is important.

Exploitation does not have to be a deliberate or conscious act by the researcher in order to occur, and can happen in many different ways. In my work with indigenous communities in Central America, my interviews inadvertently revealed several exploitive impacts that past research projects had on the community that were in no way intended by the professors and graduate students working on the multi-faceted project. As previously cited, one informant felt their ancestral knowledge had been commodified by researchers. They also suggested that the researchers' conclusions reflected what their family members had already taught them for generations, and additionally only after much disruption to their

lives. Informants mentioned that multilateral funding bought the researchers computers as well as four-wheel drive cars to navigate the territory's unpaved roads, none of which remained in the hands of the community organizations with whom they worked after the project concluded. While several local leaders were able to negotiate with the graduate school to carry out additional consulting projects on more locally urgent topics with the original funding, many of those results never made it in to local decisionmakers' hands. Meanwhile, locals had to take time out of their schedules over the period of several years to guide and protect graduate students and professors studying issues in the deeply forested area.

Data Integrity

There are a number of ways that the accuracy of your data may be compromised when working with informants if safeguards are not put into place beforehand. One major risk is that your presence in the community will change the very variables you are studying during or after the research, which can be worsened if you are not attentive to the local dynamics of the area you are studying. Without being aware of the ethical challenges in your chosen case, you may favor certain variables or indicators that actually hide the effects on other important variables. For example, if you are working on economic empowerment in conflict zones, you may be looking at employment or schooling statistics but completely missing data and informants broken down equally by gender, which reveals a very different story.

Another main risk is that participants may not give truthful or fully truthful answers under a number of circumstances where they fear the consequences of participation or non-participation. For example:

- If your informants are being coerced into participation, e.g.: employees required by employers, prisoners who may not feel they are able to make voluntary decisions due to their incarceration, children volunteered by parents/guardians, spouses volunteered by their partners.
- If your informants *feel* they are being coerced into participation through threat or reward by a third party, e.g.: they view your request to participate as a mandate based on some sort of power dynamic at play, their employer pays overtime for participation, their teacher gives extra credit for participating. Depending on the financial situation of your informant, compensation may not be viewed as a vital necessity, thus, blurring the lines between voluntary and coercive participation.
- If your participants are nervous about your ability to maintain their confidentiality and fear repercussions.
- If your recruitment process does not take into account cultural or historical realities of your sample and inadvertently leaves out subgroups causing sampling bias, e.g.: those without internet access, women who are not allowed to speak to male researchers without a chaperone, groups that have been abused by scientists in the past and are suspicious.
- If something about you personally is seen by the potential participant as:
    - Irrelevant (uninterested in the topic, many researchers have come before with no positive outcomes);
    - Inappropriate (not someone the informant should be talking to);
    - Intimidating (some characteristic that inspires fear).

I will elaborate on a few of these scenarios to paint a clearer picture of the possible consequences to your data. If an employer tells an employee that they cannot go home until they talk to you, that is coercion. The employee may only give answers that allow them to leave as soon as possible. They may worry they will lose their job if they do not give the answer that they think their employer wants to hear. Even with promises of confidentiality, the fear of losing their job may lead them to answer with what they think you or their employer wants to hear, therefore they may express views that are not their own.

Research saturation or fatigue is another common ethical issue that also affects data integrity. If informants in a well-studied region perceive you as just another researcher coming through for an interview with little benefit to them, they may not be very interested in giving you many details – if they decide to participate at all. On the other hand, an informant may feel intimidated or have some other sort of pre-conceived notion about you given a demographic category you represent such as nationality, ethnicity, skin color, or gender. As a result, they may answer questions differently than they might have if the researcher represented an alternative demographic category. These sorts of concerns are broadly known as positionality concerns, which require understanding 1) the position of the researcher relative to the social, environmental, economic, racial, cultural, historical, etc., context of the research, and 2) what influence the resulting researcher/informant power dynamic may have on the data collected.

To illustrate the data accuracy risks of overlooking context, I turn to a story shared by a colleague of his research on deaths during heat waves. Their team was trying to determine the reason that women died at higher rates during these extreme climate events than men in rural India. When he went to interview women, he found no new information. When a female member of the research team went to speak to them, they instead shared critical pieces of data: 1) women in this area need to go to the bathroom outdoors due to a lack of indoor plumbing, but 2) previous incidents of sexual assault while seeking a place to relieve themselves have led them to only go to the bathroom in the evenings when male family members came home from work and can accompany them. As a result, they stopped drinking water during the day to avoid urinating, leading to higher rates of death from dehydration. In this case the gender of the researcher very much mattered to the participants, and determined what information they chose to share and the resulting conclusions drawn.

Part II – Research Design

A careful research design is a powerful tool to minimize these ethical concerns in human subjects research. Just like controlling for newly discovered confounding variables, you will have to continuously re-design your research as you find holes where ethical challenges have not been fully addressed.

One overall design option that explicitly seeks to avoid exploitative relationships is using a participatory research approach. Such approaches have been popular in health research and promoted in additional IR-related areas such as development, public policy, civic engagement, and other social sciences like sociology and anthropology. These approaches may go by slightly different names, but their fundamental principle is that the researcher works in equal partnership with the target population from the beginning to define the research problem all the way through data collection and analysis. It is important to ensure co-learning between academic(s) and community members, capacity building, mutual benefits for all partners, and a commitment to solve some sort of disparity/inequality through the research in the long-term (see Israel et al. 2003; Wallerstein and Duran 2006).

In addition to participatory methods, there are other ways in which ethical concerns can and should be addressed through your research design. In the remainder of this section, I will discuss choosing methods, instruments, field sites, and your sample.

Methods & Instruments

The most common methods for working with human subjects in the social sciences include experiments, surveys, interviews, focus groups, field observations, using pre-existing data sets with identifiable information, or any combination of these methods. Fellow authors in this volume have gone over each of

these methods in detail in Part IV; my job here is to focus on the ethical issues to consider when choosing and planning for these methods.

Many social scientists are aware that all human subjects research participation must be voluntary and informed. But many researchers may not be aware that it is a Western and/or privileged position to expect human subjects to participate in science and data collection for free. This expectation can reinforce an implied asymmetrical power dynamic: the informant should be grateful to the researcher for including them, or for contributing to "science." While this may not be the researcher's intention – and many IR students may indeed see irony in this interpretation, given their often-joked-about low status and funding – many of the institutions built around such interactions underpin this perception by informants.

Thus, the data collection process should explicitly value participants' contributions, rather than solely extract information from them. This does not mean you have to offer money, but you do need to offer other benefits to show you respect people's time, candor, autonomy, and informed decision to participate. This is particularly important when employing interviews, as participants usually have the most demanded from them time-wise (see Mosley 2013). First and foremost, be up front if there is no payment for participation, and give the option to follow up with the participant to share your results in the language of their interview as soon as it is feasible. Some additional non-monetary ways to reciprocate:

- Do your research ahead of time to avoid asking questions that are offensive, or are easily answerable through other means to avoid wasting their time.
- Offer to pay for a meal, beverage, or snack during the interview.
- Offer a ride to/from the study location, or a transportation voucher.
- Let interviewees choose their interview location.
- Provide a trusted translator to remove the burden of speaking in a second language from the participant.
- Give participants the power to schedule interview times.
- Be cognizant of childcare necessities or other related concerns in order for interview subjects to participate.
- Facilitate access to the results of any past research done on their community.
- Provide other relevant information to participants that is related to your topic of study, i.e. resources for finding more information on immigration concerns if you study migrants, on grant agencies if you study development, on the latest relevant trade news if you study rural markets.
- Include open-ended questions in your instrument so that the participant can offer information they think is important, rather than always be confined to pre-set answers.
- Add on a final open-ended question where you ask the participant what they think should be studied.
- Ask the participant if they need any other information or assistance that you might be able to provide, or link them up with others who can assist them.

This last one can be difficult. Certainly, I have been asked for assistance outside of my purview to provide. However, I am sincere with the participant in that moment about what is possible as related to their request and/or provide feasible alternatives. The bottom line is that researchers seek to foster interactions that yield the requested data, while equalizing any power asymmetries between them and their informants.

Using randomized control trials (RCTs) to evaluate results are growing in popularity across IR fields. When it comes to any experimental designs, there is an additional ethical concern that should be contemplated carefully: dividing populations into control and treatment groups when the treatment is an intervention that can have significant consequences for the participant. Examples in the IR field might include giving a medical remedy to one community, offering school vouchers, implementing a new voting system to reduce corruption, trying a new conflict resolution program, and so on. A driving ethical principle in experiments in the medical field – where RCTs really began - is *equipoise:* researchers should not know if the study participants will be better off under the treatment or control conditions. But fields like the social sciences have not widely adopted this ethical approach, even if their interventions obviously violate this principle (for example, see Bédécarrats, Guérin, and Roubaud 2020; Evans 2021 for the pros and cons of RCTs in the economics and international development fields, and specifically Abramowicz and Szafarz 2020 for a discussion on equipoise). While RCT results can be very valuable to see if these interventions work, such interventions can have significant impact on the lives of participants and generally should be offered to the control group upon completion of the experiment.

Finally, there are different levels of ethical concerns for data collected in-person versus virtually. I will speak in more detail about in-person collection in Part IV. However, virtual collection typically has fewer confidentiality concerns then in-person because the researcher can more easily avoid some of the undesirable situations already mentioned: there is no chance for someone to see you with an informant and infer participation, there is less opportunity for someone to know if an informant was paid, there is less identifying information available to the researcher. In an internet survey, the researcher can leave out identifying questions or advise the participant beforehand to leave questions blank if they do not want to share the information. They also can avoid collecting the users' ISP information for further protection. And since it is less likely for the researcher and informant to interact if participation is asynchronous (no audio or video), the virtual medium also removes positionality concerns. In virtual interviews, the researcher and participant will most likely interact through audio and/or video, but the researcher still does not need other personal information such as an exact geographical location of the participant, allowing them to maintain more anonymity.

Location and Sample

While the location and population sample you chose for your study is driven by your research question, you still must consider the long history of ethical concerns regarding social science researchers from developed countries heading to developing countries to collect data (Lunn 2014; Scheyvens 2014), from former colonizers heading to former colonies (Madison 2020), men collecting data from women (Scheyvens and Leslie 2000; Wolf 2018), and from countries in peace to conflict zones (Cronin-Furman and Lake 2018), among others.

These ethical concerns center on the possibility that the researcher will take advantage – knowingly or unknowingly – of a vulnerable population. A vulnerable population is generally defined in human subjects research as a group of people who are vulnerable to coercion or undue influence. For example:

- Informants living in conflict zones, because they often have fewer human subjects protections in general due to a lack of laws or law enforcements and an overall weak government during a conflict, meaning they may feel coerced into participation. On the other hand, they may feel that their participation will win them special favor with the researchers, who they believe may offer assistance or protection.
- Children and prisoners, as they are both groups with diminished autonomy. Prisoners also have a long global history of being involuntarily subject to experimentation.
- Pregnant women, because research must not harm either the pregnant mother or the fetus.

- Those who primarily speak a different language than the language of the study, as you must ensure that the individual understands all risks and responsibilities in order to give informed consent.
- Anyone without the ability to fully understand the informed consent as presented.
- Low-income individuals, who may feel coerced into participation to obtain compensation.
- Indigenous groups, who are impacted, often negatively, by governments operating on their native lands without any sort of an informed consent process, consultation, or representation.

While not always included in official categories of vulnerable populations by ethics boards, there are many other populations that also logically fall under this category. Women who live in places with high levels of gender violence may avoid male researchers. Locations that have endured any form of colonialism, imperialism, or other type of oppression may view research as continuing an extractive relationship: the researcher collects private information from participants for their personal benefit. Countries where certain ethnic populations have been subject to involuntary and unethical experimentation, such as the Tuskegee Study in the U.S. that targeted Black men, or Nazi testing on groups including the Romani and Jews in concentration camps, have rightfully caused those populations to be suspicious of researchers as have modern day institutional structures that perpetuate biased care among different demographics.

You need to take the particular circumstances of your target population, vulnerable or not, into consideration in the design process. One important way to avoid ethical conflicts in your research design is to think through any potential power dynamics at play if you were to visit X country and/or X population, and attempt to remove power asymmetries (Sultana 2007). Take a low-income rural context, for instance. Participants may notice the type of rental car you drive to their community, the clothes you wear, the technology you may bring. In my and many colleagues' experiences, women often face additional scrutiny in what they wear, their physical appearance, if they are pregnant, or other questions about their personal lives and/or whom they are traveling with. Now take an elite interview. These informants may change their answers based on the researcher's nationality due to past or current political relations. In contexts where locals have seen many researchers come through to study a particular topic, they may feel like they are being constantly bothered by outsiders who take up their time for projects where they never see the results, and thus have no incentive to speak to you. Consider what you could do in each situation to decrease the power differential with your informants – or even if you should visit that community at all, versus hiring locals, or another trusted person to speak to that population.

Additionally, you can cause a breach of confidentiality and/or harm when working with people in a location that could be easily identifiable. If you are interviewing a group of political opponents to the current government in a secret location, and you mention the setting of a nearby landmark or it shows up in your pictures, you may give away their location. As a general rule, if the location is known for being one of the few places that does X or has X in the country, leave this information out of all write-ups.

Part III – Formal Ethical Approval

If your study fits the definition of human subjects research in your institution or country, or the country or territory where you will be collecting data, you are subject to the rules of those bodies. Many require formal pre-approval processes. Additionally, many peer-reviewed publications require proof of human subjects research approval before publishing.

Ethics approval processes such as Institutional Review Boards (IRBs) are often viewed as an obstacle or a way to stop researchers from pursuing their research goals, as opposed to a way to ensure your informants' remain safe and are participating on an informed and voluntary basis. While not every researcher may agree with the specifics of their institution's ethics process, bodies such as IRBs rarely push back on any well-considered social science research. In fact, the applications themselves are the easy part, when compared to the challenges of developing your research process to address potential ethical concerns.

Since every country and institution has its own requirements, I will not focus on specifics here, but rather general advice for preparing applications. However, I will emphasize that although something listed here may not be required in your specific situation, it does not mean you should not think through the issue. If nothing else, I hope this chapter imparts the need to consider ethics in your research far beyond any formal requirements, as they cannot possibly anticipate all the ethical dilemmas that may arise in each individual study.

Navigating Human Subjects Approval Processes

If you have determined that your research indeed fits the definition of human subjects research (or if you are unsure if it does), contact your institution's research office or equivalent to inquire about the process. This office will be the most important resource you have in navigating any formal approval processes and should be viewed as a support for your research and ethical questions.

Formal procedures tend to work as follows:

1. Many ethics approval processes first require an online training and certification for the researcher, and students generally need a professor on record as the principal investigator in the study.
2. If you are not using a pre-existing questionnaire, write up your instrument with the questions you anticipate you will ask informants.
3. Write up your anticipated recruitment process for potential participants.
    a. How will you get in touch with possible informants in both a scientifically rigorous and ethical way? As you recruit individuals who meet your criteria to participate, you need to consider the ways in which any sub-groups may be inadvertently left out in the process. Being aware of ethical concerns in your selected sample is vital to avoid sampling bias. For example:
        i. If you recruit by email, you risk leaving out anyone without secure Internet access, which could also bias your sample along socioeconomic, racial, geographic, or ethnic lines.
        ii. If you plan to go door-to-door in a neighborhood where individuals have had poor experiences with researchers in the past, they may actively avoid you, leaving out an important part of your research sample.
        iii. Some female-identifying participants may choose not to participate in a study on sensitive topics with male-identifying researchers.
    b. If you are emailing your potential participants to recruit them, you may want to include some sample questions from your instrument. You should attach your informed consent document, so that they are aware of exactly what is expected of them, including whether or not they will receive compensation.
4. Write up the data collection process, and exactly what will happen with participants if they agree to your study.

    a. Take the reader step-by-step through the who, what, when, where, how, and why of your expected interaction with the participant.
    b. The more choice you give to the participant to control the circumstances of the interaction, such as the location, day, time, etc., the fewer ethical concerns over whether their participation is truly voluntary. This may mean scheduling extra time on site and patiently waiting for informants to confirm with you once in the field.
    c. Consider if you will audiotape or videotape interviews. Recording your participants could leave them more vulnerable to exposing their identity, so it should only be done when there is a compelling reason to do so, e.g. if the interview is in another language and needs to be transcribed/translated, or you are specifically interested in the words informants use or the nonverbal cues they offer.
5. Assess the risk and benefits of participation (see more on this topic in the next section). You can only assess this once you have chosen your methods, so you can properly envision the data collection scenarios that could harm or benefit informants. If you are not comfortable with either, re-think your research design.
6. Consider who will have access to the data, in what form, and your data storage plans once the study is over: where will their data be kept (if it will be kept) and how will it be protected. For example, you can destroy the audiotapes once the interviews are transcribed and remove any identifying information from the transcripts, to protect the confidentiality of your participants in perpetuity.
7. Gather all this information and put it into your informed consent document, which I will discuss in greater detail in the next section.
8. Submit your application with as much anticipation as possible. Ethics boards often back up at certain times of the year, such as the end of academic terms and right before summer, and you may not collect data until your study is approved. They may also ask you additional questions or to make some changes, so you want to give yourself sufficient time.
9. Be sure you follow your own protocols during and after the study concludes. The requirement to protect your informants lasts for as long as your data exists, not just for the duration of the study.

Again, the staff at your research office should be happy to answer your specific application or general ethics questions.

Informed Consent Document

These documents have many different parts and a lot of standardized text, and individual ethics board usually have their own informed consent template available online. Their purpose it to make sure that your potential participants know what is expected of them and can make an informed decision about participating. They generally consist of sections such as:

- Introduction to the study
- Description of what the participant will be asked to do
- Risks
- Benefits
- Compensation
- Confidentiality
- What happens if the participant wants to stop mid-study
- Alternative mediums of participation
- Contact information of the researchers and ethics boards

To properly fill them in, you will need to stay attentive to the following issues and decisions in your document:

- Be truthful and informative in the introduction to your study without giving away your theory or hypothesis to the participant when they read it, so that you are not leading the participant's answers in the direction of your hypothesis before you even begin.
- Obtain explicit approval to be audio or video/taped.
- Obtain explicit approval for use of any names or other identifying information.
- Include a clear statement about what identifying factors about each participant you will use.
- Include a clear statement if you would like the participant to allow use of their data in any future research.
- Include a clear statement about who will have access to any identifiable information, and your data storage plans once the study is over.
- Include a clear statement explaining any benefits.
- Include a clear statement about any risks or harm that the participant may be subject to.
- Decide whether you would like written or verbal consent. If your study has minimal risks, many ethics bodies prefer verbal consent, as there will be no paper trail after the study with the participant's name or information on it.
- Your document will probably only be approved in the language of the ethics board; however, you will then need to translate those documents into the language of data collection for your participants.

Ethics Boards Regulating Your Field Site

You also need to determine any additional human subjects ethics requirements you must follow for field sites in other countries and on indigenous lands. Again, these approval processes are not optional and can result in serious consequences for the researcher if not followed, such as refusing entry to the country in the future, fines, criminal consequences, etc.

- Although not comprehensive, the U.S. Department of Health & Human Services provides a list of ethics standards in 133 countries including the U.S.: https://www.hhs.gov/ohrp/international/compilation-human-research-standards/index.html
- Many indigenous groups also require their own ethics review process before performing any research with indigenous groups or land. In the U.S., a list of Tribal IRBs provided by the Indian Health Service can be found at: https://www.ihs.gov/dper/research/hsrp/instreviewboards/

Assessing Risk and Benefits

A risk is generally defined as the probability that a participant will be harmed – physically, emotionally, professionally, or in any other manner – during the research study. Ethics boards are specifically evaluating if the benefits of participating in the research outweigh the risks. Most social science research will contain only minimal risk, meaning that it is comparable to the risk that the participant could experience in everyday life or when taking part in routine exams. However, the risk could be amplified if say deception is involved, or any biological measurements are taken.

Minimal risk studies often include statements in the informed consent document such as: the participants may feel uncomfortable during interviews especially if any sensitive topics come up; the participant may feel uncomfortable sharing their opinions in front of others in a focus group; etc. Consider under what circumstances your participants may feel uncomfortable speaking with you or another research team member, and how you can minimize the risk. For example, if you are speaking to women who have been

victims of wartime rape by men, you may want to only have women interviewers. Again, your positionality as the researcher is a critical factor to take into account when assessing potential harm for your informants.

A benefit, on the other hand, is something the participant will gain as a result of participation. If there is no payment, generally benefits are stated in the informed consent along the lines that the participant may enjoy contributing to understanding X phenomenon, and adding in any of the other ways you may choose to give back to participants as previously discussed. There may be no benefits for a participant in your research study. Either way, when assessing benefits to participation, you should reflect on whether there is an exploitative dynamic at play.

Part IV – Ethics During Data Collection

Once you have completed your research design and been approved to work with informants by all relevant ethics board of your institution/countries, you may be making a visit to your field site or preparing to collect data. As researchers doing fieldwork know, anything can happen in the field, but there are ways to prepare ahead of time for possible ethical dilemmas.

Positionality and Privilege

Reflecting on positionality requires understanding the position of the researcher relative to the social, environmental, economic, racial, cultural, historical, etc. context of the research and what influence any resulting asymmetrical power dynamic may have on the data collected. There are some measures you can take to reduce power differentials and improve the integrity of your data while in the field. Examples include:

- Do a lot of research ahead of time on your site, and network with locals to the best of your abilities to better understand the context and gain the trust of your informants. This may take extra time, but it will also avoid wasting your and your informants' time in the long-run and increasing the quality of your data.
- Be aware of any privilege you may have before walking into a situation. Privilege is when a special right or advantage is given to a particular group of people, including groups defined by immutable characteristics such as nationality, skin color, gender, age, physical attributes, etc. The mere fact that you were able to freely travel to that country may represent your privilege if your informants cannot do the same due to income or visa restrictions. Even the institutional seal that may come on your informed consent documents will convey a message to your informants about your status. Do everything possible to ensure your informants do not perceive those characteristics as coercive or a reason to give answers they believe you will like.
- Do not be defensive if participants bring up any of your elements of privilege.
- If you cannot use local forms of transportation, rent an economic class vehicle that is still safe for the terrain you will be working in. Be similarly cognizant of your choice of lodging, if it is a factor known or obvious to informants.
- Wear the same clothes/accessories and carry the same items when meeting with each informant, no matter the day.
- Be consistent in your answers to any personal questions informants ask you, always attempting to steer the conversation back to professional topics or the research at hand.
- Be sensitive to any speakers who are speaking in a non-native language with you and their level of fluency. If you sense that you are not understanding one another as well as you hoped, be sure that you take the time to check-in with them or clearly explain concepts in your interview script.

If you are not sure that both sides understood one another, you may need to leave that data out of your final analysis because you cannot be sure that consent was informed.
- Always schedule extra time at a field site, to give your participants ample time to speak with you at their convenience. This may mean extra money on limited research budgets, so plan accordingly.

There may be situations where you will not be able to fully research your locations, as you need to travel to the area to search for appropriate locations/participants. I once did an impact evaluation at a past development project site in an unincorporated community whose name was not on any map. The original project implementers were no longer sure exactly where it was, as it was one of many communities they had originally worked with. Having just the general region where it was located, I needed to travel to the most likely sites and ask locals until I located the small rural community I was looking for. As a result, I needed to spend a few extra days in that general location while I quickly researched about the specifics of that community, and their historical and political contexts as I went into the data collection phase.

Recruitment

When recruiting participants to be in focus groups or interviews:

- If you are using the snowball method for recruitment, be sure that the referred person knows you will not notify their recommender if they participate, nor anyone else.
- If you contact the potential participant via a third-party organization or institution, be sure the participant knows you are not affiliated with that group in any way and are an independent researcher.
- If meetings are virtual, be sure you chose a platform that does not keep data on meetings in their system.
- Include the informed consent document when contacting individuals and explain what it is, since many people will be unfamiliar with this document or its purpose.
- Be cognizant about who has access to any shared calendar entries where you write down identifying information about your informants.
- Be on the lookout for power dynamics between participants when putting together focus groups. For example, putting an employer and employee together in the same group may make the employee feel uncomfortable to express their true positions out of fear they could lose their job. This could also be true for including family members or couples, who may fear repercussions at home for truthfully participating in discussions.
- If meetings are in person, have consent forms printed out in the appropriate language to distribute to the informants once you meet them. Always have extras on hand in case you meet additional informants in the field.
- In virtual surveys, put the informed consent document as the first question and receive the participant's affirmation they agree by pressing a button to continue – no need to sign anything.

When recruiting participants for virtual surveys, you may use a service that recruits for you, like Amazon's Mechanical Turk or a survey company. Be sure you understand the confidentiality policies of that platform or company because their privacy policies still fall under your ethical responsibility. What information do they collect? Do they keep ISP numbers?

If you need to perform household surveys by going door-to-door, there are additional ethical concerns that may arise. If you are cold calling – showing up unannounced – recognize that you could appear as a threat to the resident. Even though you mean no harm, you may cause distress to the resident simply by

approaching their residence, and furthermore compromise your data by deterring an informant from answering your questions. You can try to alleviate this by wearing clothing that clearly announces the institution you are with, any official name badges, dressing professionally, carrying your survey materials in hand to give a clue as to why you are coming to the door, and respecting the residents' space. Ring doorbells first. Do not enter doors or gates even if open – call from outside with your name, affiliation, and/or purpose.

Exceptions to Confidentiality

In research involving minimal risk to the participants, generally there are no explicit exceptions to keeping your informant's identity confidential. However, if a situation does come up where the informant reveals serious information, for example about a crime or a threat to hurt themselves or others, please get in touch with your institution's ethics board right away to determine how to proceed and what other reporting laws you may need to comply with.

Taking Photos on Site

Photos make a world of difference for a presentation or website, helping viewers see the situation on the ground in your research context. It is a fast and simple way to help your audience better understand your research justification, methods, challenges, and results. However, publishing a picture of you holding a focus group with informants easily identifies who you spoke to, especially if this presentation is publicly available online or part of your webpage. This violates typical confidentiality agreements.

The photos you take need to be in line with your ethics board application – if the location of the project is explicitly mentioned in your research and you informed your subjects of this before obtaining their consent, then pictures identifying that location can be used. But if you refer to a community you worked in with an alias, then the photos you take must make it extremely difficult to identify that location beyond say its general country context.

Finally, it is important to always respect the dignity of your subjects when photographing them. There is a difference in showing the general situation of a research site as opposed to specifically seeking out particular images of a community to sell an idea of poverty, or wealth, or some other sort of stereotype to the outsiders. Power dynamics can easily be reinforced by who is behind versus in front of camera lens. Your subjects need to be asked for permission to be photographed and told how the image will be used. You want to avoid at all costs that your photograph subjects feel like they are a tourist attraction or that their living situation is a sort of novelty that will be published for the world to see, particularly if on a public social media account.

Social Media & Public Websites

Indeed, a popular trend among researchers is to post real-time photos of fieldwork on social media accounts. Keeping followers updated on current work makes your account engaging and interactive, but posts, photos, and captions can reveal a host of information about your informants that could have swift consequences, including putting you and them in danger. For example, in sensitive country contexts and/or with vulnerable populations such as domestic abuse victims or whistleblowers, this information can be used to identify the location of individuals.

Such digital information is also much easier for the general public to access than a peer-reviewed article, especially if location, hashtags, or user tags are included that easily identify place, topic, organization, or individual. A simple internet search can easily link those people with more detailed results mentioned in articles or books that are later published by the same author. Embedded digital information in original

photos on posts or on websites, such as dates and geotags, can be accessed by those with even a little tech savvy. Again, the information available through your posts must be consistent with your informed consent, otherwise it should not be published.

Being Prepared

Be sure that your poor planning does not become the responsibility of your informants. Strive to be prepared for a variety of challenges in the field so that your participants do not need to get you out of a tight spot, especially if it is a vulnerable population. Examples include:

- Car failure
- No cell phone signal
- No potable water on site
- No food available on site
- No lodging available on site
- Extreme climates
- Poor roads
- Toll roads
- Unreliable public transportation schedules
- Theft

Part V – Describing Results

Once the research is done and data is analyzed, you still need to think about ethics and protections when writing up results. You should first review your consent document and take note of what information you told informants you can use, as it must be consistent with what you originally stated in that document. Temporarily hide all other non-usable identifying information in your database to remind you about what information can be included when describing your results (for general data storage guidelines, see Jamieson and Salinas 2018). Additionally, here are some reminders about common mistakes researchers make in this process.

Quoting

Unless you have obtained specific permission to use your informant's name, you may not use it when directly quoting an informant. Furthermore, you may not directly quote your informant if you did not write down word-for-word what they said or transcribe it from a recording to which the informant agreed, you can only paraphrase their words in these cases.

Identifying Information

You may not have used your informant's name, but a description such as "the only female mayor in the X state" would still easily identify the person and should not be used. Even if you told your confidential informant that their title and state would be used, you have given enough combined information that the can still be identified, which does violate the confidentiality agreement. A phrase like "a female mayor in a X state" can be used if A) there are many female mayors in that state, and B) you told your informant that their gender, title and state would be used in their informed consent.

If you are using a pre-existing database, you may have access to confidential data. Similarly if you are performing an evaluation, you may have access to non-public information about the project or program that you use to create your own research conclusions. In these cases, be sure you do not reveal any identifying information of participants in your write-up, especially since you are not sure what people

agreed to originally in any previous informed consent, nor have you administered a new one. Check with your institution's ethics board about any additional requirements you may have when using this data with identifiable information.

Pictures

Again, be sure any pictures you include in your write-up cannot identify subjects or any other information they did not consent to reveal.

Informal Conversations

If you have an unexpected conversation with someone outside of your normal research protocols (i.e. an informal conversation not originally intended as data collection and thus no informed consent) that gives you some insight into your research problem, be sure that any information you include from such conversations makes the informant completely non-identifiable. If the information itself that they gave you can identify them, you need to contact them and obtain their informed consent and/or contact your ethics board for advice.

Conclusion

For IR researchers, working with human subjects can offer an invaluable source of data. Such studies offer a nuanced view of the diverse problems we study; they shed light on decision-making processes, incentives systems, preferences, cultural influences, individual and group perceptions, the list goes on. As valuable as we deem this information, human subjects research can come at a considerable cost to the participant without proper protections in place. Ethical approval boards like IRBs, while helpful in addressing some of the fundamental ethical concerns with human subjects research, cannot address the full breadth of ethical issues and potential harm that such studies can pose. Therefore, the onus is on the researcher to take proper steps to minimize risks and ethical dilemmas to participants – for as long as the resulting data exists, not just the duration of the study.

In navigating the ethics of human subjects research, researchers must ensure their informants' participation is fully voluntary and informed. But they also must account for the harm that could come to informants from both their direct and indirect actions, from precautions they may fail to take, and importantly from who participants are and the categories they represent - including the positionality and the power differential between researchers and participants. Dr. Xaxa's words are an important reminder we should always return to in order to keep research grounded in humanity and reality:

> *I am not your data, nor am I your vote bank,*
> *I am not your project, or any exotic museum object,*
> *I am not the soul waiting to be harvested,*
> *Nor am I the lab where your theories are tested….*
> *- Abhay Xaxa (2016)*

In this chapter, I have offered a framework to guide researchers through ethical concerns in an attempt to curtail them. But beyond prevention, I also entreat readers to seriously consider the broader ethical implications of their studies that tie to the historical and cultural contexts where they do research. A sincere exploration of their own positionality and power dynamics that undoubtedly influence the data collection process will not only value and protect research participants, but increase the integrity of data collected in IR and all social science research.

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