

An Introduction to Research Ethics and Participatory Research

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I've been asked to give quite a broad overview of research ethics. As we have a range of people in the room, from a variety of backgrounds, I'm going to do what is basically an idiot's guide to research ethics, and along the way I'll give a few examples of participatory research and some of the ethical considerations which arise when conducting it.

Participatory research as a term is used to describe a set of research methods, and also an ideological perspective. Essentially, it's where the subjects of the research are involved in the study – their knowledge and abilities are recognised and contribute to the research.

Would you please put your hand up if you've ever done a piece of research that involved collecting information from other people, whether it's a piece of formal research for a university course or an evaluation of something like an event or an exhibition?

And can you keep your hand up if you had to do a formal ethics application or evaluation as part of that?

OK now could you please put your hand up if you have ever done training in research ethics either as part of a university course or any other training?

Thanks. And now could you put your hand up if you have ever done GDPR training?

Great. The reason I asked about GDPR is that even for those of you who have not done any formal training in research ethics, some will have done training in GDPR and there is some crossover between the things that we consider as ethical researchers and what we think about as data controllers.

Introduction

Four key principles of ethical research:

- ▶ Avoiding harm
- ▶ Ensuring informed consent
- ▶ Protecting the right to privacy
- ▶ Avoiding deception

As I said I'm going to begin with a basic overview of ethical norms in social science research. The essential principles of ethical research can be divided into four key areas: avoiding harm, ensuring informed consent, protecting participants' right to privacy, and avoiding deception. Nearly everything that arises when considering doing any kind of ethical research, or considering the ethics before you do something involving collecting information from people (or talking to people or interacting with people) as part of a piece of research can be categorised under these four areas.

Of course, because sociology researchers deal with people, of which there are an infinite variety, there are exceptions to all of these rules.

So now I'm going to take you on a whistle stop tour of those four principles and some of the situations which may arise within them.

Avoiding Harm



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First of all, prevention of harm. This doesn't only mean harm to the participant; it also includes harm to the researcher. And harm doesn't always mean something physical: taking part in research can cause participants stress, result in a loss of self-esteem, or could mean that they do something within the context of the research which they would never normally do and which could cause significant distress.

The 1960s and 1970s are full of examples of research which is extremely ethically dubious as far as causing harm to participants is concerned. I'm sure that most if not all of you have heard of Philip Zimbardo's Stanford prison experiment, and Stanley Milgram's obedience experiment.

Avoiding harm to participants relates closely to the ethical principle of the right to privacy. However, we have a broader responsibility as researchers. And so one of the things of which we must inform our participants is that if we believe that they may cause harm to themselves or to anyone else, we have the obligation to report that suspicion and seek to prevent that harm.

Sometimes, harm is unavoidable; no matter how well prepared we are, or how well we prepare our participants, reactions can be surprising. In participatory research, where personal relationships may have been built up over days or weeks or years, the end of the study can bring on feelings not unlike grief.

And, for all that I massively disagree with them, many of the psychology studies conducted in the 60s, 70s, and 80s did provide some interesting and useful results. And, if nothing else, they provide useful case studies for discussion in ethical training sessions!

Ensuring Informed Consent



"Consent is Sexy" by ctrouper is licensed under CC BY 2.0.

The second foundational principle of research ethics is that of informed consent. In order for a participant to give informed consent they must have been provided with a clear description of the study, of what their participation will entail, and be aware that their participation is voluntary and can be withdrawn at any time (within reason and within the context of the study).

Consent is an ongoing process. A participant has the right to change their mind regarding their overall inclusion in the research, or their level of anonymity, or whether they wish for their quotes to be included in the final write up. And this change of mind can take place at any point during the life of the project – though, as I said earlier, within reason.

If, for example, you are doing an evaluation of an event or an exhibition or a performance and the data that you collected includes the number of people who attended who were in specific age brackets or of specific genders, or information about the favourite part of the exhibition, then that data would likely be amalgamated into the whole, so if a participant said that they didn't wish any of their answers to be included but that data analysis had already been done it would be very difficult to remove their data. Not impossible, but difficult. Equally, if your research has involved interviews or questionnaires or focus groups, it might be quite simple to remove the quotes from one specific participant.

Part of the information which we provide to participants when we ask them for their consent is the way in which their information is going to be used. For a lot of research within universities this is likely to be publication in academic journals or books, or presentation as part of a conference. For research which is conducted outside of academia this may also mean books or articles, although not necessarily from academic presses; it may mean newspaper or magazine articles, government publications, and any number of informal publication methods. Either way, it is good practice to inform participants of where your work is likely to be made available, and also to inform them if that changes.

This is a significant crossover with the GDPR, which also states that data must be collected for clearly defined purposes and should not be used or sold for purposes other than those which the participant agreed to. Even when data has been depersonalised or pseudonymised It may be possible to reconstruct the original information, so using it for a different purpose should **not** be done.

Consent can also be linked to the principle of protection from harm. One of the considerations when planning research is how to avoid including those who may not be able to provide informed consent. Children, people with specific learning difficulties, people with dementia, for example. There are circumstances in which it is difficult to know whether or not the people that you are interacting with have the capacity to fully understand the implications of taking part in the research. For example, a lot of my research is done online and it's very difficult to know whether the people that you are speaking to actually fit the criteria that you require for your participants. For example are they over 18, are they from the UK, are they female? This is often a complication for Internet-based research, but may also arise in other situations.

Protecting Privacy



"Masquerade mask from Roger's Gardens" by Kerri Lee Smith

Research participants have the right to privacy if they require or request it. In the cases of some research it is not only individuals who require privacy, but the community that they reside or participate in. Providing participants with anonymity and confidentiality is standard practice for most Social Research. In many cases the researcher or the research team are the only ones who have access to information which would identify their participants; in some cases, once the data has been collected it is pseudonymised and the original, identifying information is not even available to the researchers.

Participants might ask not to be made anonymous in the write up of your research, for example because they want to “go public” with their views. This decision has to be balanced against other considerations, such as any potential risk of harm to that participant, or the possibility that the use of their real identity could impact on the anonymity of other participants.

The use of appropriate data storage, whether physical or digital, is an integral part of maintaining the confidentiality of research participants. Again, similar to the GDPR regulations, research data must be stored securely and deleted when it is no longer needed for the purposes of the research.

Avoiding Deception



"Crossed fingers I" by Katie Tegtmeier is licensed under CC BY 2.0.

The final principle to consider when designing ethical research is the use of deception. Obviously, in an ideal world, no one would use deception in order to gather research data. Unfortunately, sometimes it is necessary to use some level of deception. Some researchers argue that life is full of small deceptions, and that it's no worse than telling a small white lie, which is justified by the results achieved. The question when looking at the topic of deception in social research is, where is the line? The line between being completely open and deceiving participants to a greater or lesser extent is not necessarily in the same place as the line between ethical and unethical practice.

Observation is a frequently used method in social science, and is a key element of ethnography. As a method it does tend to use deception. Because there can be significant differences between reported behaviour and observed behaviour, watching the way that people behave or react is more reliable than asking them to report on their behaviours and reactions. There are a variety of ways of conducting observational research, both structured and unstructured, and in the majority of them the participants are not aware that they are being observed. Deception is, therefore, inherent in these methods - but how else can a researcher try to record and understand the behaviour of a specific group or community? It is one of the most interesting and frequently discussed areas of research ethics.

In Conclusion:

Ultimately, the majority of principles, considerations, rules, guidance... for conducting ethical research can be boiled down to one phrase (and I apologise for any offence caused by the next slide):

Summary:



"Don't Be a Dick" by bump is licensed under CC BY-NC 2.0.

Don't be a dick.

But Seriously...



"Kittens!" by nicsuzor is licensed under CC BY-SA 2.0.

In summary, ethics are enormously important in all people-centred research. Researching and investigating and observing and understanding other people and their experiences is a privilege, but that privilege comes with obligations. And although it is true that there are exceptions to almost everything that I have stated as a rule today, those rules are necessary.

How can we justify choosing to make those exceptions if we don't know the rules, and understand why they are so vital?

Thank you.