# Chapter 10
# Research Ethics Step by Step


## Contents



This chapter has been co-authored by Dorota Lepianka.

**Electronic Supplementary Material:** The online version of this chapter (https://doi.org/10.1007/978-3-030-48415-6_10) contains supplementary material, which is available to authorized users.



J. Bos, *Research Ethics for Students in the Social Sciences*,
https://doi.org/10.1007/978-3-030-48415-6_10

**After Reading This Chapter, You Will:**

- Have a general knowledge of Institutional Review Board (IRB) procedures
- Have the capacity to anticipate the basic ethical pitfalls in research designs
- Know how to counter common ethical objections
- Be able to design an informed consent form

**Keywords** Added value · Anonymization · Avoiding harm · Benefits · Conflicting loyalties · Cost-benefit analysis · Data management · Data storage · Deception · Doing good · Equitability · Ethics creep · Expenditures · False negatives · False positives · Gatekeepers · Informed consent · Intrusive questioning · Invasion of integrity · IRB · Loyalty · Privacy · Protocols · Pseudonymization · Reciprocity · Relevancy · Responsibility · Risk assessment · Seeking justice · Trust · Vulnerability

## 10.1 Introduction

### *10.1.1 Research Design and Ethical Approval*

In this chapter, we aim to guide you through some of the most important ethical issues you may encounter throughout the process of finalizing your research design and preparing it for the process of ethical approval. The issues discussed here range from broad topics about the relevancy of the research itself, to detailed questions regarding confidentiality, establishing informed consent, briefing and debriefing research participants, dealing with invasive techniques, deception, and safe storage of your data.

The majority of these ethical dilemmas coincide largely with the concerns voiced by independent *Institutional Review Boards* (IRBs, also referred to as *Research Ethics Committees*, or RECs). IRBs register, review, and oversee local research applications that involve human participants. They are established to protect the rights of research participants and to foster a sustainable research environment. The task of such boards is to evaluate whether or not a research design meets the institutional ethics standards and facilitates a necessary *risk assessment*.

The necessity of ethical reviewing is reflected in national laws as well as international declarations and has become a mandatory procedure in universities and research institutes worldwide (see Israel 2015, for an overview of ethical reviewing practices). Failing to seek the approval of an IRB can have serious consequence for the researchers involved. For example, the retraction note attached to an article on bullying, published in 2017 in the *International Journal of Pediatrics* revealed 'The study was conducted in agreement with the school principal and the authors received verbal approval, but they did not receive formal ethical approval from the designated committee of the Ministry of Education' (entry at 'Retraction Watch', March 13th 2019).

A number of scholars focusing on ethical review processes have critiqued the institutionalization of ethical reviewing, because, as one author observed, it seems to assume that unscrupulous researchers are restrained only by the leash and muzzle of the IRB system (Schneider 2015, p. 6).

Indeed, by setting aside ethics as a separate issue and submitting it to an 'administrative logic' (procedural, formalistic approach), scholarly research has fallen prey to a form of *ethics creep,* a process whereby the regulatory system expands and intensifies at the expense of genuine ethical reflection (Haggerty 2004). Scott (2017) remembers how a simple study once was killed by such formalistic procedures. Understandably, researchers sometimes see the completion of an IRB application form to be a mere 'formality, a hurdle to surmount to get on and do the research' (Guillemin and Gillam 2004, p. 263).

We agree that ethical considerations should inform our discussions about research, and that these discussions should not be obstructed by regulatory procedures. The aim of this chapter is therefore to assist you in your ethical deliberations. This chapter seeks to guide you through the process of making important ethical

decisions at all stages of formulating a research design, and to help you identify the common pitfalls, objections, and critiques. To facilitate this process, we have designed a series of queries at the end of each paragraph, that could be taken into consideration whenever you plan to carry out a research project. Not all questions may be relevant to all research projects, but as a whole, they should facilitate a fairly thorough preparation.

In the sections to follow, we map out the various ethical dimensions of designing a research project step by step: addressing the fundamental question of why and for whom we do research (Sect. 10.2); an exploration of the ethical considerations of the research design itself, including the recruitment of study participants (Sects. 10.3 and 10.4); violation of integrity (Sect. 10.5); avoiding deception (Sect. 10.6); informed consent (Sect. 10.7); collecting data during field work (Sect. 10.8); what to do with incidental findings (Sect. 10.9); analyzing collected data (Sect. 10.10); reporting and dissemination of research findings (Sect. 10.11); and finally data management and storage (Sect. 10.12). This chapter closes with a summary (Sect. 10.13) and we include a brief ethics checklist and offer a model informed consent form that can be used in the future to help you cross all your 't's and dot all your 'i's (Box 10.1).

We highlight our discussions with multiple case studies selected from a wide range of disciplines within the social sciences, including specializations within psychology, anthropology, educational sciences, interdisciplinary studies, and others. For the sake of brevity, we refrain from seeking examples from all disciplines for each individual dilemma, but instead focus on those that seem most poignant. We hope this overview will prepare you to face the rigors of research with confidence.

## 10.2 Relevancy: Choice of Research Area

### *10.2.1 What for?*

There are few subjects or questions that researchers cannot study, but are they all worth researching? That is a different question. Contrary to what you may think, completely new research questions do not exist. Research builds upon the pre-existing research lexicon. In fact, researchers have an obligation to enhance or critique theories, improve established bodies of knowledge, and adapt or alter relevant methodologies.

Failing to acknowledge research traditions may come with the risk of wasting valuable resources, but also of self-disqualification. The relevancy of a research project is thus not so much measured in terms of how *much* knowledge it generates, but rather in how much knowledge it generates *in relation to what is already known* (see the imperative of originality, discussed in Chap. 2).

**Box 10.1: Rules of Thumb for Ethical Assessment of Research Designs**

1. **Avoiding Harm** Researchers have a responsibility to ensure that their study does no harm to any participants or communities involved. They also need to assess the risks that participants (and communities) may face.

   How likely is your research project to cause harm to the individuals or communities you choose to research? How serious is the possible harm? What measures need be taken to offset the risks? Is there any way in which harm could be justified or excused? How do you ensure that your study does not endanger the values, cultural traditions, and practices of the community you study?
2. **Doing Good** Researchers have the complementary obligation to do research that contributes to the furthering of others' well-being.

   Who are the beneficiaries of your study? What specific benevolence might flow from it and for whom? What can participants reasonably expect in return from you and what should you offer them, if anything? What does your study offer to promote the well-being of others? How does the community or society at large benefit?
3. **Seeking Justice** Finally, researchers should ensure that participants are treated justly and that no one has been favored or discriminated against.

   Do you treat your participants fairly and have you taken their needs into consideration? How do you ensure a fair distribution of the burdens and benefits in both the participant's experience and research outcomes? How are the (perhaps contradictory) needs of the communities taken into account?

Whereas all three criteria seem 'self-evident' if not trivial, there remains the critical and difficult question of *how* to interpret them, and whether they apply in any given case (i.e. everybody will agree that one should not harm people and do good or seek justice but what does this mean in practice?). For further discussion, see Beauchamp and Childress (2001), *Principles of Biomedical Ethics*.

### *10.2.2 For Whom?*

Some research is fundamental – for the sake of knowledge – but most is not. Often, results have certain practical uses for other parties, sciences' *stakeholders*. They can be *commissionaires* who act as patrons of research projects, *professionals* working in a 'field of practice' who make use of scientific knowledge, or their *clients.* Research can have implications for policy makers, teachers, therapists, professionals working with minority groups, or indeed, minority groups themselves, to name but a few.

The question how research projects impact various (potential) stakeholders is not always explicitly addressed, but we feel that this is something that deserves careful

attention. Who is addressed, who will be influenced, and who can make use of research in which ways? Consider the following two examples where the stakeholders are specifically targeted and even addressed.

1. Ran et al. (2003) describe a comparative research study into the effectiveness of psychoeducational intervention programs in the treating of schizophrenics in rural China. The program specifically targets patients' relatives, who, the researchers conclude, need to improve their knowledge of the illness and change their attitude towards the patient.
2. A qualitative study on experiences with prejudice and discrimination among Afghan and Iranian immigrant youth in Canada singles out the media as a 'major contributor to shaping prejudicial attitudes and behaviors,' and schools as one of the first places youth may encounter discrimination (Khanlou et al. 2008)

### *10.2.3 At What Cost?*

Thirdly, there is the question of balancing costs and benefits of research. *Costs* comprise of salaries, investments, use of equipment, but also of sacrifices or (health) risks run by all those involved. *Benefits* can be expected revenue and earnings, but also gained knowledge and expertise, certain privileges allotted to participants, or even access to particular facilities.

The fact that the costs and benefits can be of a material and immaterial nature makes them both difficult to measure and predict (see Diener and Crandall 1978). How do you value and weigh costs and benefits? Who should profit and who should run which risks?

While there is no way to answer these questions in general, there are different models that you can use to assess risks and benefits, based on what you think counts as important.

In the first model, science is committed to the *principle of impartiality*. Researchers and research participants partake in research primarily because they value science, want to promote its cause, and feel that their contribution helps further scientific knowledge. In this model, costs consist just of the salaries of the researchers and the marginal compensation of the participants for their time. Knowledge acquisition is the most important gain, and risks are understood in the immediate context of research (health hazards).

In the second model, knowledge production is regarded as a commercial activity. Universities and their researchers are seen as entrepreneurs who collaborate with other parties (mainly industry and government) and are committed to the *principle of profit*. In this model, costs are seen as investments, gains as (potential) revenues. Compensation of participants is an expense item and any risks they run can be 'bought off.'

The third model proposes knowledge production from the *principle of equitability* (fairness for all). It accepts that knowledge may be profitable, but rejects a

one-sided distribution of gains, where all the profits (patents, publication, prestige, grants) go to the researchers only, and none to the participants. Participants should not merely be monetarily compensated, but profit in a much more direct way, for example by giving them access to health facilities, providing better knowledge of the topic in question (Anderson 2019) or even empowering whole communities (Benatar 2002).

These different models not only perceive parties or stakeholders differently, they also perceive of risks, costs and benefits differently. Consequently, researchers may come to weigh the costs, benefits, and risks differently depending on what they value most (Box 10.2).

### *10.2.4 Trauma Research: A Case in Point*

Consider the question of whether research on traumatic experiences itself should be regarded as harmful. It is argued, on the one hand, that asking about traumatic experience is risky, as survivors may be more vulnerable and easier to stigmatize. On the other hand, there is also evidence that suggests that talking or writing about traumatic experiences can in fact be beneficial, psychologically as well as physiologically (Marshall et al. 2001). How does one weigh the (potential) risks against the (possible) benefits (DePrince and Freyd 2006)?

**Box 10.2: Fair Compensation?**
In a research application for a study on coping with undesirable social behavior at the workplace in China, the researchers planned to ask participants to complete a questionnaire which was estimated to takes up to 15 min. Participants would receive ¥8 (roughly 1 Euro) in compensation for their effort, but only once they completed the questionnaire. When queried by their local IRB why every participant wouldn't be compensated regardless, rather than only those who complete the questionnaire, the researchers presented four arguments:

1. Rewarding participation before finishing the research leads to high drop-out rates
2. It is difficult to organize payment with non-completers
3. The questions are non-invasive
4. In comparable cases, applications are always approved by IRBs

Evaluate these responses by ranking the arguments. Which argument do you find most and which least convincing, and why?

(Case communicated to one of the authors of this chapter)

In a study among 517 undergraduate students, Marno Cromer et al. (2006) asked subjects to rate how distressing it was for them to discuss a range of traumatic experiences and found that a vast majority did not find it difficult at all. However, argued the authors sensibly, it's not the *average* that counts here, but the *exception*. And indeed, 24 participants reported the trauma research to be 'much more distressing' than everyday life. Of these 24, all but one still believed the research to be important enough to be carried out. The one exception reported that the research seemed 'a somewhat bad idea.'

These findings concur with Newman et al. (1999), who did research on childhood abuse and found that a minority of the respondents reported feeling upset after the research. Of these, a few indicated that they would have preferred to have not participated had they known what the experience would be like.

In weighing the (immaterial) benefits against the costs of talking about traumatic experiences (distress), the former were deemed to outweigh the latter, provided that interviewers are carefully selected and trained.

Of note, however, one consideration is left out of this comparison, namely the question of whether *not* doing the research should be considered a risk (Box 10.3). Indeed, Becker-Blease and Freyd (2006, p. 225) reason that 'silence is part of the problem', and there is a real 'possibility that the social forces that keep so many people silent about abuse play out in the institution, research labs, and IRBs.'

Will the cost-benefit balance shift if the risk of *not* doing research be taken into consideration?

**Box 10.3: Risks and Benefits**

**Risk**: The probability of harm (physical, psychological, social, legal, or economic) occurring as a result of participation in a research study. The probability and the magnitude of possible harm may vary from minimal (or none) to significant.

**Minimal Risk**: A risk is considered to be minimal when the probability and magnitude of harm or discomfort anticipated in the proposed research are not greater, in and of themselves, than those ordinarily encountered in daily life or during the performance of routine physical or psychological examination or tests.

**Benefit**: A valued or desired outcome, of material or physical nature (i.e. money, goods), or immaterial nature (i.e. knowledge, skills, privileges). Individuals may not only benefit from the research, but also communities as a whole.

(Adapted from the Policy Manual of the University of Louisville.)

**Q1:** What is the added value of my research project and for whom does it benefit?

- Which research traditions and methodologies do I relate to and why?
- Who is addressed by my research project (who are my possible stakeholders)?
- Which costs and benefits can be expected, for whom, and how do I balance them?

## 10.3 Choice of Participants

### *10.3.1 Ethical Limitations in Choice of Participants*

Researchers must make many decisions regarding the choice of participants. Is the sample randomly selected and does it give a fair representation of the population? Will the *N* be large enough to test my hypothesis? Has non-response been taken into account? Et cetera. Some of these methodological questions have ethical consequences, as we will explore below.

### *10.3.2 Number of Participants*

This is of ethical concern because research is considered (at least to a degree) a burden on participants and often times on society at large as well. The number of participants should therefore be no more than absolutely necessary.

In quantitative studies, a reasonable estimate can be given with a *power analysis*. 'Statistical power' in hypothesis testing signifies the probability that the test will detect an effect that actually exists. By calculating the power of a study, it becomes possible to determine the required sample size, given a particular statistical method, and a predetermined degree of confidence. For example, to detect a small interaction effect between two variables, using a linear mixed-effect method, a sample of N = 120 would suffice at a default alpha of .05. Remaining space in this book does not permit a detailed discussion of how to calculate the power of a study, but see Cohen 1988, for an explanation of power in the behavioral sciences in general.

In qualitative studies, no such power analysis would be suitable. Instead, the principle of *saturation* is often used. Saturation implies approaching new informants until enough knowledge is gained to answer the research question, or until the categories used are fully accounted for. What exactly constitutes 'saturation' may differ from one field of expertise to the next and may need further problematization moving forward (see O'Reilly and Parker 2012).

### 10.3.3 Selection of Participants

Laboratory studies often use undergraduate students as research subjects (usually in exchange for 'credits'). These are called *subject pools*. In some fields of research in the social sciences, subject pools make up the majority of research participants, as Diener and Crandall (1978) pointed out long ago.

*Convenience sampling* (using groups of people who are easy to contact or to reach) not only has methodological drawbacks, but also ethical implications. Heinrich, Heine, and Norenzayan (2010) called attention to the social science's 'usual subjects' and named them WEIRDOs, an acronym for Western, Educated, Industrialized, Rich and coming from Democratic cultures.

They maintain that WEIRDOs aren't representative of humans as a whole, and that psychologists shouldn't routinely use them to make broad claims about the drivers of human behavior because WEIRDOs differ in fundamental aspects with non-WEIRDOs. Different cultural experiences result in differing styles of reasoning, conceptions of the self, notions of fairness, and even visual perception.

### 10.3.4 Online Communities

As a specific target group for research, online communities pose their own dilemmas. Legally, researchers must be aware that they may be bound by the 'general terms and conditions' of these online platforms, which can restrict the use of their data for research purposes. Morally, it is important to ask whether it is right to record the activities of an online public place without the participant's consent, regardless of whether it is allowed (see Chap. 7 for a discussion of this question). There are two viewpoints we will explore on this matter.

Oliver (2010, p. 133) argues that although communication in an online environment may be mediated in different ways, it is still communication between people. In essence, the same ethical principles should apply, including the receipt of active consent.

Burbules (2009, p. 538) on the other hand, argues that in online or web-based research, notions regarding privacy, anonymity, and the right to 'own' information needs to be radically reconsidered.

What matters online, Burbules argues, is not so much anonymity, but rather access. In the digital universe, people *want* to share information. But they also want to *control* who can make use of it. A challenging dichotomy to navigate indeed.

This problem (the question of who can access which data) has become even more urgent today. This urgency can be traced to new information and communication technologies that enable researchers to build extremely complex models based on massive and diverse databases, allowing increasingly accurate predictions about an individual's actions and choices.

### *10.3.5 Control Groups*

Research on the effects of certain interventions that involve *control groups* (participants who receive either less effective or no treatment) leads to the question of whether it is fair for a participant to be placed in a disadvantageous position.

This is referred to as *asymmetrical treatment*. The question is grounded in considerations of *egalitarian justice*, which is in other words, the idea that individuals should have an equal share of the benefits, rather than just the baseline avoidance of harm.

It is suggested that participants in the control group be offered the more effective treatment once the study is completed (Mark and Lenz-Watson 2011). A problem with this being that it applies to certain research designs only (typically RCT, or 'Randomized Controlled Trial') and not to others (policy interventions, for example, or education; for further discussion, see Diener and Crandall 1978). With research on policy interventions, (as opposed to treatment research), the question is whether or not it is fair to offer certain policies to certain groups and not to others.

**Q2:** Who are the participants in my research project?

- Which ethical consequences may be involved in selecting participants for my research project?
- How do I ensure that my selection of participants does not result in unfair treatment?

## 10.4 Vulnerable Participants

### *10.4.1 Vulnerable Participants*

*Vulnerable participants* are properly conceived of as those who have 'an identifiably increased likelihood of incurring additional or greater wrong' (Hurst quoted in Bracken-Roche et al. 2017). Seeking the cooperation of vulnerable people may be problematic for various reasons, but that does not imply that they cannot or should not be involved in research. It does mean that these groups need special attention, however.

### *10.4.2 Minors and Children*

Working with minors and children requires consideration from both a moral and a legal perspective. Often in place are somewhat arbitrary age limits that will differ from country to country, which require that researchers seek active consent from the

parents or legal representatives of a child. This says little, however, about the minor's moral capacity to participate in research.

IRBs generally acknowledge that children can be involved, but that different age-groups should be treated on par with their stages of psychological development, that will inform what a six-year-old or a twelve-year-old child can or cannot do, or what an eight-year-old is capable of comparatively. In general, the younger the child, the shorter and less intense the inquiry should be.

We concur with Schenk and Rama Rao (2016, p. 451) who argue that young children should be excluded from providing detailed information on potentially traumatic topics that may cause strong emotional distress. As is usually the case, exceptions can be made under particular circumstances, but they remain outliers. We also agree with Vargas and Montaya (2009) that it is sensible to consider any contextual and cultural factors, as this may make a difference in a child's understanding of the research environment.

Finally, we emphasize that researchers who work with minors (children) should have special training on how to interview or collect data from them.

### *10.4.3 Disadvantaged Participants*

When cognitively impaired individuals are included in a research design, special attention must be paid to the potential level of invasiveness, the degree of risk, the potential for benefit, and the participant's severity of cognitive impairment (Szala-Meneok 2009). Likewise, people who are in *dependent circumstances* (such as detainees, elderly people in nursing homes, or the unemployed), may not always have the capacity to refuse consent, or may fail to understand that they have the power to refuse cooperation. A reasonable assessment regarding the perceived ability to participate and to refuse participation must thus be made for every case in which these populations are involved (see Box 10.4 for an overview of vulnerable participants).

### *10.4.4 Mixed Vulnerability*

At times, several forms of vulnerability coincide within one research proposal. Consider as a case in point a proposed study into health problems (suicidal ideation), sexual risk-taking behavior, and substance use of LGBT adolescents of between 16–17 years old, as reported by Brian Mustanski (2011). An Institutional Review Board (IRB) was hesitant to approve Mustanski's application for a number of reasons. We will discuss those reasons below, together with Mustanski's responses.

The first problem the IRB encountered was that the researcher was seeking a waiver for parental permission. Adolescents at this age are legally minors and any

**Box 10.4: Vulnerable Populations by Category**

| Category | **Examples** (not exhaustive) |
|---|---|
| **Cognitive or communicative Vulnerability** participants who are unable to process, understand, or appreciate consent either by mental or language limitation. Researchers targeting a population where this is likely to be present must provide a consent procedure that will accommodate the needs of participants, either by translating documents, writing it in basic language, or discussing the consent. | People with little or no literacy skills<br>People with cognitive impairment |
| **Institutional Vulnerability** this includes individuals who are subject to a formal authority and whose consent may be coerced, either directly or indirectly. A solution to this issue can be using a third party to advise on the matter, and possibly eliminate any conflicts of interest. | Prisoners<br>Student/professor relationships<br>Employee/ employer relationships |
| **Deferential Vulnerability** individuals who informally act as subordinates to an authority figure, where one party may feel obligated to follow the advice of another. These situations require a sensitive recruitment and consent plan where participants have the opportunity to consent voluntarily. | Abuse victims<br>Doctor/patient relationships<br>Husband/wife relationships |
| **Medical Vulnerability** this includes individuals with a medical condition that may cloud their ability to make decisions regarding their participation. The patient may see the research study as a miracle cure to their disease instead of a procedure that has no guarantee for results. Researchers should ensure that participants are able to understand the full meaning of the study to alleviate any misunderstanding. | Patients<br>People with incurable diseases<br>Very sick people |
| **Economic Vulnerability** this includes individuals whose economic situation may make them vulnerable to the prospect of free care and/or the payments issued for participating in the study. It is important that the payment offered will not encourage an individual to put themselves at a greater risk than they would otherwise. | Homeless people<br>Unemployed people<br>People on welfare benefits or social assistance |
| **Social Vulnerability** participants who are at risk for discrimination based on race, gender, ethnicity, or age fit into this category. The participant may also be prone to feel discriminated against and may not participate as a result of this predisposition. | Ethnic minorities<br>LGBTQ<br>Elderly |
| **Legal Vulnerability** this includes participants who do not have the legal right to consent or who may be concerned that their consent could put them at risk for legal repercussions. For those who are unable to legally consent, it is important that you obtain consent from a legal representative and in most cases also obtain consent from the individual. | Minors<br>People under legal guardianship |
| **Study Vulnerability** participants who are made vulnerable by the study's design, specifically through deception. This can be alleviated by ensuring full consent and disclosure after the study is completed (debriefing) or whenever a participant withdraws from the study. | Any participant who is subjected to deception |

Adapted with permission from the guidelines of the Institutional Review Board for Social and Behavioral Sciences at the University of Virginia.

waiver requires the provision of an appropriate mechanism for protecting the minor. Mustanski argued, however, that the goal of waiving parental permission was not to circumvent the authority of parents. 'Instead, it is to allow for scientists to conduct research that could improve the health of adolescents in cases where parental permission is not a reasonable requirement to protect the participating youth' (2011, p. 677).

The second concern of the IRB was the vulnerability of the LGBT community collectively, who have historically been more prone to stigmatization and discrimination. Mustanski replied that he knew of no evidence that demonstrated any decision-making impairment of members of the LGBT community, and that he believed many of them would be insulted to have it implied otherwise.

Finally, and perhaps most importantly, the IRB was worried that participants in this research might be exposed to sensitive information that could lead to psychological harm. Mustanski agreed that IRBs should have a role in protecting participants' interests, but argued that IRBs tended to overestimate risks. This can lead to time-consuming procedures and the implementation of supposed protections that may mitigate the scientific validity of the research, or discourage future behavioral research involving certain populations. After a number of required adjustments (such as a more detailed risk assessment), the proposal was ultimately accepted.

**Q3:** How do you ensure appropriate and equitable selection of participants?

- Who are your research subjects?
- Are your research subjects part of a vulnerable population, and if so, what risks do you anticipate?
- Where do you expect to find them and how do you intend to recruit them?

## 10.5 Use of Invasive Techniques

### *10.5.1 Invasive Techniques*

By *invasive techniques*, we mean any procedure or intervention that affects the body or mind of a research participant such that it results in psychological or physical harm. Some argue that our definition of invasiveness should not be limited to individual participants but should include entire communities as well (Box 10.5).

Invasive techniques, by definition, violate the *principle of nonmaleficence* ('do no harm'), and are among the most urgent concerns of IRBs the world over. However, harm is broadly (and vaguely) defined, ranging from trauma to strong disagreeable feelings, and from short-term to long-lasting. *The European Textbook on Ethics* (2010, p. 200) defines harm as such: 'To be harmed is to have one's interests set back or to be made worse off than one would otherwise have been. Harms can relate to any aspect of an individual's welfare, for example physical or social.

**Box 10.5: Invasive or Intrusive?**

The term *invasive* originates from the medical sciences, where it means*: entering the body, by cutting or inserting instruments*. In the social sciences, it describes techniques that enter one's privacy. Questions about one's sexual orientation, political preferences, and other privately sensitive subjects are considered 'invasive', as is exposure to strong aversive stimuli or traumatizing experiences.

*Intrusive* was originally a legal term, described as *entering without invitation or welcome*. In the social sciences, it describes techniques that invoke 'unwelcome feelings.' Research may be regarded as 'intrusive' when it concerns topics that respondents dislike talking about or find difficult to discuss (Elam and Fenton 2003, p. 16). Intrusive techniques can also involve prolonged procedures and processes that involve substantial physical contact. Intrusive questions can make a participant feel uneasy, uncomfortable, even shameful: 'Are you anorexic?' 'Do you masturbate?'

Some examples of invasive and intrusive technique include:

- EEG, PAT scans, CAT scans, (f)MRI, or measuring heart rate, are all non-invasive in the medical and psychological sense, but can be intrusive.
- Questions about race, ethnicity, and sexual health can be both invasive and intrusive.
- Queries about personal information, including name, date and place of birth, biometric records, education, financial, and employment history, are often thought to be neither invasive nor intrusive. However, to some people some of these questions *can* be intrusive. Regardless, use of this information is strictly limited under data protection regulation in most countries.

Institutions can also be harmed insofar as they can be thought of as having interests distinct from those of their members.'

Invasive techniques may include exposure to insensitive stimuli, intrusive interrogation, excessive measurements, or any procedures that can cause damage. We exclude from our discussion any medical practices or intervention, such as administering drugs or the use of clinical health trials and refer anyone who intends to use these techniques to specialized Medical Research Ethics Committees (MRECs).

### *10.5.2 Examples of Invasive Research*

Some of psychology's most famous experiments were hampered by the ethical quandaries of invasive research. For example, John Watson's 1919 behavioral experiments with 'Little Albert,' an eleven-month-old child, who was exposed to

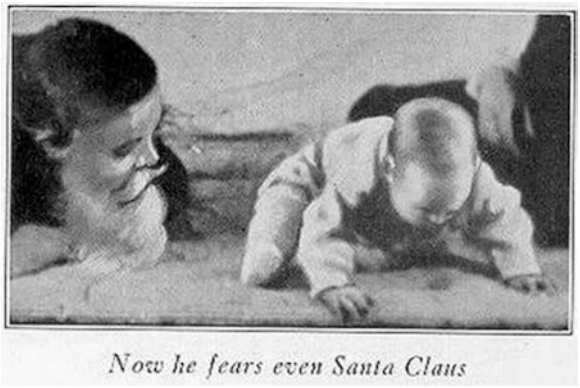


**Fig. 10.1** *Little Albert*. Still from the film made by Watson. (Source: Wikipedia)

loud, frightening sounds when presented with specific fearsome images. Although it is unclear what the net effects were on the child, by today's standards, the design would be considered unethical for its gross lack on concern for the wellbeing of the child (see Harris 1979; Beck et al. 2009) (Fig. 10.1).

Harry Harlow's 'Pit of Despair Studies' from the 1950s involved infant primates who were raised in social isolation, without their protective mothers or with surrogate mothers (dolls). They consequently developed signs of what humans call 'panic disorder.' This complete lack of concern for animal welfare would certainly be considered unethical by today's standards.

Psychologist Stanley Milgram's well-known 1961 experiments, that involved participants who were led to believe that they were administering electric shocks to fellow participants are deemed invasive, despite the researcher attempting to minimize harm by debriefing his participants (see Tolich 2014).

Diana Baumrind (1964) was quick to recognize the ethical perils of the Milgram studies: 'From the subject's point of view procedures which involve loss of dignity, self-esteem, and trust in rational authority are probably most harmful in the long run and require the most thoughtfully planned reparations, if engaged in at all' (p. 423).

### *10.5.3 Avoiding Invasive Routines?*

Can (or should) invasiveness be avoided at all times? The answer seems obvious: no techniques that cause harm should be put to use. In practice, however, the answer is more ambiguous.

Some research topics are inherently 'sensitive' (i.e. psychological trauma, loss, bereavement, discrimination, sexism, or suicide). Merely discussing these subjects can be perceived as painful. Similarly, some techniques necessitate a physical response from participants and can result in some harm. Does that imply these subjects cannot be researched, and that these stimuli cannot be used? Not necessarily.

In an experiment that provides a telling example, researchers tried to establish the causal relationship between workload and stress response. To do so, they had to induce a potentially harmful stimulus, namely some form of stress. The results showed that such stimuli do indeed have an influence on a participant's perceived well-being and impacted their physical health, as indicated by an increased cardiovascular response (see Hjortskov et al. 2004).

Is it justifiable to expose respondents to harmful stimuli, even when the effect is likely short-term? Hjortskov et al. answered the question in the affirmative and took refuge in what is considered by many as a safe baseline in research ethics. If harm does not exceed *the equivalence of what can be expected to occur in everyday life,* they argued, then the procedure should be safe.

It has been maintained that invasive techniques using stressors, unpleasant noises, rude or unkind remarks, among other forms of aggravators, are acceptable when (a) there are no other non-invasive techniques at hand, (b) the effects are equivalent to what people can expect to encounter in everyday situations, (c) have no long-lasting impact, and (d) everything is done to minimize harm.

Some retort that this will not (always) be sufficient. People who face systematic stigmatization in everyday life, or social exclusion, would be harmed in a way that is not acceptable should they be exposed to such stimuli, even though that is exactly what they expect to occur in everyday life.

**Q4:** Will the research design procedures result in any (unacceptable form of) harm or risk?

- Which possible risks of harm are feasible in this research?
- How do you plan to minimize harm (if any)?

## 10.6 Deception

### *10.6.1 Deceptive Techniques*

Any research procedure in which a participant is deliberately provided with misinformation is labeled as a *deceptive technique*. Deception involves (a) giving false information, or (b) generating false assumptions, or (c) withholding any information that participants may request, or (d) withholding information that is relevant to appropriate informed consent (Lawson 2001, p. 120). Just because early research on the harmfulness of deception does not indicate that deceived participants feel harmed (Christensen 1988) or that they become resentful (Kimmel 1998), does not mean it is without moral consequence.

By default, deception excludes consent (see below). Participants are therefore not at liberty to decide to participate (or to continue participating) on the conditions known to them, regardless of whether consent was given afterwards, or even whether participants agreed to be deceived beforehand (when they agree to be fooled in some way).

Deception thus suggests a possible breach of two important ethical principles: the protection of people's autonomy and dignity, and the fair and equitable treatment of participants. Some have called for the abandonment of deception in research altogether, while others maintain that certain research areas, particularly in psychology, cannot do without it (see Christensen 1988). At any rate, IRBs have become more cautious in the last decade and generally insist on a full debriefing at minimum (see Mertens and Ginsberg 2009, p. 331). But even a full debriefing may not always be possible.

To summarize: forms of deception include providing false or misleading information about:

- Research goals or aims
- Research setup
- The researcher's identity
- The nature of a participants' tasks or role
- Any possible risks or consequences of participation.

The distinction between *false* information and *defective* information is noteworthy. False information means presenting an (oftentimes completely) wrong picture of the true research goals, while defective or misleading information might only mean withholding some (key) aspects thereof. Some argue that not telling participants certain things is not a form of deception (Hey 1998, p. 397), but we concur with Lawson (2001) that it certainly *can* be, especially on a relational level (pertaining to the relationship between researcher and participant) (Fig. 10.2).

### *10.6.2 Four Cases*

Consider the following four cases in which (some form) of deception was deployed. How does the form and level of deception differ in these cases?

In the first, that came to the attention of one of the authors of this chapter, a group of researchers proposed to approach a number of intermediaries with mock job application letters and matching CV's that differed only with respect to the ethnicity of the 'applicant'. The researchers intended to measure the response rate of the

| | | **Information Provided to Participant** | | |
|---|---|---|---|---|
| | | Full | Incomplete/defective | None/False |
| **Type of Consent Offered** | Full consent | No deception (default) | Deception | Deception (questionable) |
| | Adhoc consent | Debriefing | Deception/debriefing | Deception (questionable) |
| | No consent | Tacit consent (questionable) | Objectionable / illicit deception | Objectionable / illicit deception |

**Fig. 10.2** Degrees of deception as a function of consent/debriefing and provision of information

intermediaries as an indication of hidden discrimination. The 'participants' (the intermediaries) were neither informed of nor debriefed about the research project, and thus would not be able to not participate or retort to its findings. Deception was deemed necessary to elicit true behavioral response.

The second pertained to an unpublished ethnographic study into social exclusion of the poor in Poland, carried out by one of the authors of this chapter. The researcher asked participants if they could be interviewed about their 'lifestyles,' deliberately not mentioning the goal of the study (social exclusion) because the researcher reasoned it might instill them (against their own conviction) with an idea that they are marginalized and excluded. The researcher feared that this idea would impose on them an identity that they could perceive as harmful. The research participants who were asked for consent were not informed about the true nature of the research project, nor were they debriefed afterwards. In this case, deception was considered both necessary as well as in the interest of the participants.

The third case concerns a covert participant observation project in an online anorexia support community performed by Brotsky and Giles (2007). The researchers created a mock identity of an anorexic young woman who said she wanted to continue losing weight. The researchers wanted to study the psychological support offered to her by the community, who was not informed about the research project. Throughout the course of the project, the invented character of the researchers developed close (online) relationships with some of its members. They justified the use of a manufactured identity on the grounds that if the purpose of the study was disclosed, access to the site would probably not be granted. Deception was deemed acceptable because of the 'potential benefit of our findings to the eating disorders clinical field' (2007, p. 96). The research participants were never asked for their consent, nor informed about the nature of the research.

The fourth case concerns social psychology research into the *bystander effect* (the inclination not to intervene in a situation when other people are present). Experiments on the bystander effect rely heavily on giving false information about the roles of other participants involved in the study, because they are in reality in cahoots with the researcher.

In a recent study into the bystander effect, Van Bommel et al. (2014) wanted to know whether the presence of security cameras would have any influence on said effect. The researchers designed a realistic face-to-face situation featuring a security camera (not featured in the control group). They exposed participants to a mock 'criminal act' to see whether they would respond or not. Immediately afterwards, participants were informed of the true nature of the setup.

In all cases, some form of deception was considered necessary, though for different reasons. Deception contributes to inequity between the research and the participant. By *debriefing* the participant (i.e. informing them of the true nature or purpose of the research), some of this can be countered under certain circumstances. In the first case discussed above, debriefing was not considered, in the second it was ruled out. In the fourth case it was part of the design by default and not questioned as such. In the third case, it *could* (and some would argue should) have been used.

**Box 10.6: Checkbox for Ethical Concerns in Social Sciences Research Design**

| | Invasive/ intrusive | Deception/false information | Exposure to risk/harm | Vulnerable participants |
|---|---|---|---|---|
| Biometrics | | | | |
| Randomized control trial (RCT) | | | | |
| Laboratory experiment | | | | |
| Experimental intervention | | | | |
| Participant observation | | | | |
| Survey | | | | |
| Online survey | | | | |
| Interview | | | | |
| Vignette | | | | |

Which research techniques do you use in your design, and to what extent is your design vulnerable to the ethical concerns above? Provide a detailed description.

### *10.6.3 Deception and Misinformation*

Arguably what matters most in considering the use of deception are found within two parameters: the degree of misinformation and the degree to which participants may give consent or can be debriefed (Ortmann and Hertwig 2002) (see Fig. 10.3). The questions any researcher must answer regardless are (1) whether or not it is really necessary to use deception, and (2) how to repair inequity if it were to be used.

**Q5:** Will the research design provide a full disclosure of all information relevant to the participant? If not, why not?

- How do you ensure your participants are adequately informed?
- What do you do to prevent deception?

## 10.7 Informed Consent

### *10.7.1 Informed Consent Protocols*

Following established *informed consent protocols* are indispensable in any scientific research and serve to ensure that research is carried out in a manner that conforms to international regulations (such as the 1966 United Nations International Covenant on Civil and Political Rights, that explicitly prohibits that anyone be subjected to scientific experimentation without their permission).

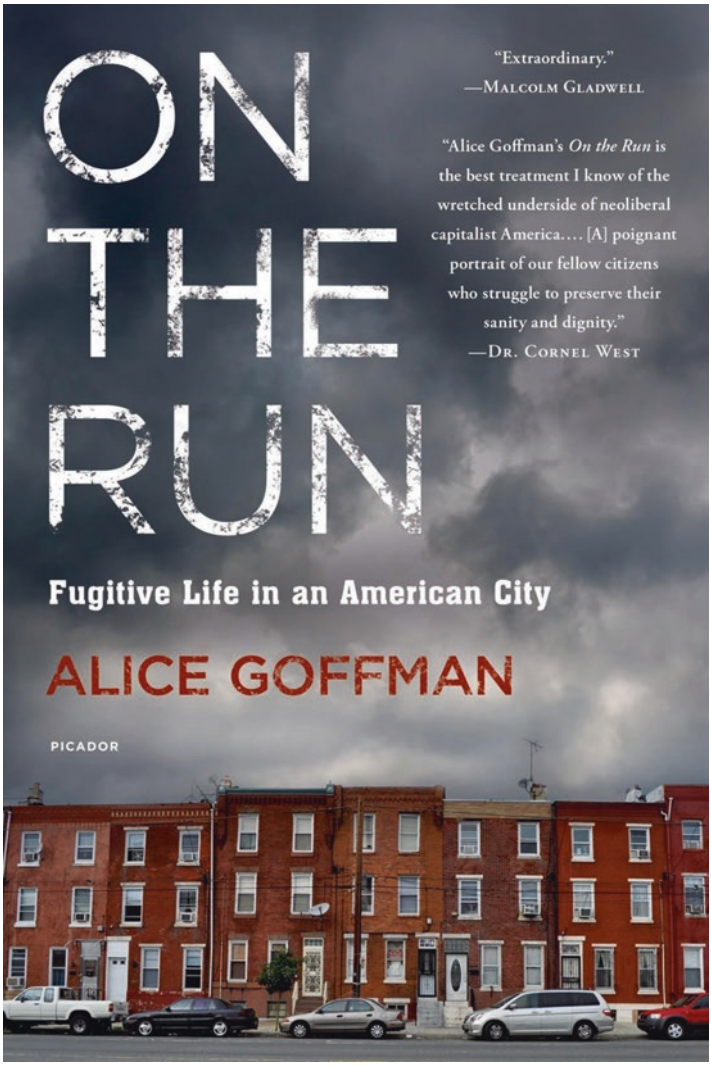


**Fig. 10.3** Alice Goffman, *On the run*

Consent is based on four prerequisites: (1) it is given voluntarily (free from coercion), (2) the participant is a legally competent actor, (3) is well informed, and (4) comprehends what is asked of them.

To inform a participant means they must be notified about the objectives of the study, be informed about what is expected from them, and be told how their data will be used. Consent requires that a participant not only has a substantial understanding of the situation in which they will partake, but is also at liberty to refuse. Consent gives the researcher the right to involve the participant in the research project and at the same time assures that the respondent's rights are protected.

Informed consent protocols assume different shapes and forms. Traditionally they were hard copy forms, physically signed by the participant. Lately, they are often digital (i.e. in an online questionnaire, the respondent is informed about the objective of the questionnaire and needs to agree by ticking a box before proceeding). In ethnographic studies, speech recordings are sometimes utilized.

Consent protocols require furthermore that participants are provided with information of whom to turn to in case of disagreement complaints, or in case of unexpected or accidental findings that may affect the participant. This can be an independent board or a professional not involved in the study.

### *10.7.2 Who Can and Cannot Consent?*

From our definition, it follows that any adult capable of understanding what is communicated to them and is at liberty to say no, can give consent. This leaves out a list of people who cannot be expected to give consent for reasons of incompetence, incomprehension, or lack of freedom. These include:

- Minors or children, who cannot legally give consent
- Adults with cognitive impairment or diminished decision-making abilities, who may not comprehend properly
- Adults in a dependent situation, such as refugees or undocumented immigrants, who may not be at liberty to refuse cooperation.

In some cases, others may consent for them (with children, this may be their parents or legal caregivers; with patients it can be their legal representatives). See Box 10.4 for an overview of vulnerability categories.

### *10.7.3 Active and Passive Consent*

Consent is by default *active*, which means that the participant is knowledgeable about the purpose of the research and actively agrees to participate in it, under the conditions spelled out to them. *Passive consent* follows a different path. The participant is informed about the research, but it is assumed that they do not object, thus *passively* agreeing to participate. The researcher proceeds *unless* the participant actively refuses to participate.

Passive consent results in higher response rates and was more commonly sought after until the first decade of the twenty-first century. Today, a stricter view on subject autonomy is held, and consequently many IRBs no longer condone its practice, allowing it only in exceptional situations (Rangle et al. 2001).

### *10.7.4 Whose Responsibility?*

It is the responsibility of the researcher that the participant fully understands what the research amounts to. The information provided must be comprehensive, to the point, and non-technical. Participants should be aware that they may refuse to (further) participate, withdraw their consent, and have their data removed from the study at any time (Box 10.7).

In some cases, it can be challenging to obtain informed consent, especially when participants are not accustomed with formal, written discourse, or come from a cultural background where such a formal permission would raise suspicion (see Israel 2015, for further discussion on the pitfalls that informed consent may carry, especially in qualitative research) (Box 10.10).

In other cases, consent may need to be re-negotiated. This can occur in longitudinal studies where parents earlier agreed that their children could participate in the study, but the child meanwhile grows up and becomes an adult capable of making their own decisions.

### *10.7.5 Disclosure of Sensitive Information in Consent*

Researchers are obliged to conceal information that might be damaging to the respondent's reputation or affect their position within their community, organization, professional field, or could have an impact on their employability. For this reason, some institutions request that their researchers report only on data larger than a certain n-value, to prevent others from finding out who the participants may be (i.e. the Karolinksa Medical Institute at Stockholm set the norm at $n > 6$).

Such considerations are of relevance even when the study participants had, prior to their involvement in research, expressed their consent or even a wish to stay *non*-anonymous. The latter might happen with participants who are politicians or activists, who might treat their participation in research as a means to get publicity.

**Q6:** Have you obtained informed consent?

- What information have you communicated to your participants?
- In what ways have you ensured they are aware of what is expected from them?
- Check with your local IRB for samples of an informed consent and/or guidelines (see end of this chapter for a sample).

**Box 10.7: Informed Consent as a Universal Principle?**

Although *informed consent* is accepted world-wide as a necessary requirement for research, the question can nevertheless be posed whether or not it is biased in favor of a Western notion of liberal individualism. Would the moral conception and ideal of informed consent be applicable in China, whose cultural and ethical traditions are often conspicuously different from those of the West, and are more specifically communally oriented (Nie 2001)?

Liang and Lu (2006) did research on legal reforms in China, for which they conducted interviews. When seeking informed consent, they ran into what they called a conflict between the *rigidity* and *inflexibility* of informed consent and the *relativity* and *informality* of Chinese culture. For Chinese participants, consent would be regarded not so much as a legal formality but rather the foundation for continued friendship and trust. Consequently, they'd be hesitant to sign a consent form beforehand.

Furthermore, Chinese participants have a different view on the legal system. While Americans trust the confidentiality agreement because laws protect privileged information, in China no such laws or legal practices exist. As a result, Liang and Lu wrote, 'a mere promise of confidentiality from the researcher to the participant would indeed raise red flags about the legitimacy of the research, therefore hurting rather than helping one's research' (2006, p. 166).

Tangwa (2014) exemplifies the situation of West African women, who because of bride-price practices, are in unequal and therefore vulnerable relationships. These women are required by their communities to get approval from their husbands if they volunteer to enlist in medical research; by insisting only they themselves can give consent, their cause will not be furthered.

Castellano (2014, p. 278) argues that the interests of Aboriginal peoples are not served with individualized consent procedures. The implementation of ethical standards for Aboriginal research should be in the hand of Aboriginal peoples. National committees should be formed, consisting of Aboriginal experts, who could develop such standards, and help prevent misrepresentation and stereotyping, and ensure that environmental research is included.

In these and similar cases, individualized informed consent procedures are all but appropriate. Instead, consent extends to communities, experts, or special committees, who oversee that interests of certain groups are served.

## 10.8 Fieldwork and Data Collection

### *10.8.1 Entry Strategy and Conflicting Loyalties*

When planning data collection, some considerations must be taken into account regarding strategies to access the 'field' (be that a school, a municipality, an internet community, or any another institute that houses participants) (Eysenbach and Till 2001).

Sometimes formal approval is required, other times approaching participants necessitates little more than the go-ahead from the head of an institute. Particularly when studying relatively small, tightly-knit communities or groups, caution is required. In those cases, researchers make use of *gatekeepers*, such as institutions or persons who have (direct) access to potential study participants. While gaining access to a field via gatekeepers has its obvious advantages, it may also involve some moral dilemmas.

*Gatekeepers*, just like research sponsors and research participants, usually have their own stake in research. When offering access to their networks, gatekeepers show trust and expect loyalty. Researchers thus engage in what is called *relational ethics*, which builds on mutual respect, dignity, and connectedness between the researcher and researched (Ellis 2014, p. 4), although the researcher often cannot avoid politically embedded issues of power that require a 'delicate balancing act' (McAreavey and Das 2013).

### *10.8.2 Cooperation and Non-Cooperation*

Once people agree to participate in a study, the researcher may count on their cooperation and benevolence. At a minimum, participants should not feel deceived, intimidated, or otherwise uncomfortable with the research, but there can be many other valid reasons why participants decide to leave a study. In some cases, such as in evaluation studies that involve a researcher's prolonged presence in the field (perhaps even against the wish of some of the actual study participants), participants may become reluctant, mistrustful, or even non-cooperative. In other cases, participants my leave studies for no apparent reason at all (as they are free to do).

Research using large databases of raw, unstructured public data ('big data') poses its own ethical considerations, in particular with regard to privacy. In consumer behavior research, for example, Numan and Di Domenico (2012) observe that the volume and speed with which data must be analyzed often requires data collecting and analysis without an individual providing specific consent. This raises ethical concerns 'relating to the extent to which organizations can control the collection and analysis of data when there is limited human involvement' (2012, p. 51).

Finally, there is the question of non-cooperation (or counter-cooperation), which can occur in a variety of ways. Researchers may find that participants avoid

answering certain questions, are purposefully manipulative, or even lie about particular issues (because of shame or to protect their dignity).

All these forms of non-cooperation will pose researchers with a challenge, and it is therefore advisable to think ahead to strategies for what to do in case there are not sufficient data points to work with.

### *10.8.3 Interpersonal Dynamics*

Ethical dilemmas may also arise as a consequence of interpersonal dynamics, both between the researcher and the study participants and (or) among study participants. In any case study that involves participant observation or repeated interviews with participants, continued interaction is likely to result in emotional and social engagement on the part of the researcher. This may lead to the formation of alliances and conflicting loyalties. As a result, the role of the researcher as an 'objective observer' of social life might be challenged.

In the course of any study, the researcher's relationship with the gatekeepers or sponsors may also need to be renegotiated, for example, when gatekeepers try to influence the direction of the study. Commitments related to confidentiality and anonymity may need to be re-affirmed or redefined. Finally, in cases of intensive ethnographic observations, the prolonged presence of the researcher is also likely to re-define the community or group or organization studied, and may raise (moral) questions related to the role of the researcher and their relationship with the object of investigation (Mikesell et al. 2013) (Box 10.8).

**Q7:** How do you enter the 'field'?

- Which formal or informal agreements have you made and with whom?
- Which expectations have been created when an agreement on cooperation has been made?
- How do you deal with non-cooperation on the part of study participants?
- How do you deal with competing loyalties?

## 10.9 Incidental Findings

### *10.9.1 Incidental Findings in Clinical Research*

Any research, including the most non-invasive varieties, can unearth *Incidental Findings* (IFs). For example, brain imaging research may bring to light undetected, clinically relevant abnormalities that are unexpectedly discovered and although unrelated to the purpose of the study, they may require urgent or immediate referral (Vernooij et al. 2007).

**Box 10.8: Alice Goffman – What are the Limits of a Researchers' Involvement?**

Sociologist Alice Goffman's 2014 ethnographic study *On the Run: Fugitive Life in an American City* details the careers of poor black men in West Philadelphia. She paints a bleak picture of these men who follow 'the other path into adulthood,' leading them invariably to crime and eventually incarceration.

In the wake of the 'Black Lives Matter' movement, the book was received with ample praise. Goffman's central claim, that it is the legal system itself creating crime and dysfunction in poor black communities, was supported by her critics, although some reviewers would argue that Goffman's views are rather one-sided. For example, Heather Douglas (2014) wrote that Goffman refused to acknowledge that her participants create their own predicament through deliberate involvement in crime.

From a research ethics viewpoint, *On the Run* raises an alarming question about the limits of a researchers' involvement. Some accounts in the book suggest that Goffman was so thoroughly involved with her participants that she became complicit in criminal activity herself, including even conspiring to commit murder (as one participant confided in his plans to kill someone). She thus violated perhaps the most basic precept of scholarly (and personal) responsibility – not to endanger somebody else's life, and to do no harm (Lubet 2015). Whether she committed any crimes cannot be established, as she had carefully concealed the true identity of the participants involved and destroyed her field notes, which from an ethical viewpoint is also questionable.

This raises the question of what to do with these findings. Is it in the interest of the participant that the researcher notifies them? The intuitive answer may be yes, but some argue that this is not evidently the case, as participants have a right *not to know*.

On the one hand, Miller et al. (2008) argue that clinical investigators do have an obligation to respond to incidental findings. They argue this point because the researcher entered into a professional relationship with the research participants, and thus they are granted privileged access to private information with potential relevance to the participants' health. Appelbaum et al. (1987) on the other hand, warn against the false hopes that a confusion of roles might create, when participants feel that research protocols are designed to benefit them directly rather than to test or compare treatment methods.

Incidental findings call for the weighing of *false positives* (potential harm due to findings that have no clinical significance) against *false negatives* (failure to report

a finding linked to a serious health problem). In an attempt to solve at least part of this quandary, IRBs often suggest that participants be offered an 'opt-in' / 'opt-out' choice in the informed consent. 'Opt-in' necessitates the researcher to communicate any accidental findings relevant to the participant, 'opt-out' prohibits the same.

However, even with such clear-cut arrangements, the researcher may still find it ethically problematic to remain silent when the participant chooses to 'opt-out' and a clearly identified, life-threatening, treatable condition is discovered (for further discussion see Illes et al. 2006).

### *10.9.2 Incidental Findings in Non-Clinical Research*

DNA analysis is increasingly utilized in forensic anthropology, for example to identify damaged or fragmented human remains, for which DNA of family members is required for proper identification. Parker et al. (2012) argue that the increased prevalence of incidental findings (IFs) in non-clinical research (such as misattributed paternity or false beliefs about sibling relationships), calls for new policies to focused on *minimizing* the discovery of IFs.

**Q8:** How should you deal with incidental findings?

- Which agreements have you made with your participants regarding any potential incidental findings?
- Do you offer an opt-in/opt-out option in your informed consent?
- How do you check for any unintended consequences of discovering incidental findings?

## 10.10 Analysis and Interpretation

### *10.10.1 Analyzing Results*

While fraud among academics is rare, questionable research practices do occur, leading to multiple forms of bias. These include (among others): *publication bias* (non-publication of null results), *confirmation bias* (tendency to look for confirmative results, disregarding of contradictory information), and *funding bias* (tendency to support the study's financial supporter) (Box 10.9).

We believe that it is vitally important that researchers are aware of the forms of bias that lie in wait and operate as transparently as possible (see Chaps. 5 and 6 of this book for an extensive discussion). Below, we discuss three issues related to bias, namely *significance*, *plausible objection*, and *limits of interpretation*.

**Box 10.9: Transparency: Steps Researchers Can Take to Reduce the Risk of Bias**

Dr. Daniele Fanelli: 'The way out of [bias], generally speaking, is to be transparent about what you did. I'm not naive enough to think that this is going to be the whole story, because publication space in journals is limited, and you will never be allowed to tell precisely everything that you have done. So in part, the system does need other ways also to allow researchers to make fully public their data, you know, all the results they obtained, etc.

Again the ideal to follow, I think, in any kind of research, is as much as possible, be transparent of the whole procedure. What were your original research questions, how you collected the data, what eventually was the data that went into this particular study, and so on.

(From online course site Epigeum, Research integrity: arts and humanities, module 3).

### *10.10.2 Significance*

After having collected data, the main concern of a researcher is whether or not the data has a story to tell. Are the results indeed significant? Is the effect a sizeable proportion? Is there a convincing narrative pattern discernable in the interviews?

Given the study produced at least *some* results worthy of discussion, then the ethical question is: are the results significant and unique enough to warrant publication? This is not self-evident nor easily established. What is 'significant' in this context does not depend on a statistical or discursive measure, but on an overall evaluation of the results. This evaluation would also include the question of whether the phenomena observed was properly accounted for by available theories. Finding (statistically) significant results is one thing, finding something that is substantial is something else. It is the task of the researcher to carefully assess the weight of their findings.

### *10.10.3 Plausible Objection*

Complementary to the question of significance is the question of *plausible objection*. One must ask themselves, if a study produces data containing significant results, how do those results line up with rivalling theories or other plausible explanations and objections? How do we know that novel findings were truly revealed, and not merely an exception to the rule, chance findings, or even false positives?

Again, the answer to these questions cannot be established on the basis of the data alone, but they need full consideration, nonetheless. The place to address these

considerations is often in the discussion section of a scientific paper or as an addendum to the findings, although in reality they should precede any discussion of the findings.

### *10.10.4 Limits of Interpretation*

Findings worthy of publication need to be framed such that their significance can be understood and eventually be communicated to others. But how far can our interpretation go?

In 2002, the then United States Secretary of Defense, Donald Rumsfeld, conceived of a way to interpret uncertain knowledge. He invented a concept that since found its way into scientific parlor: the 'unknown unknowns.' It plays a role in a distinction between 'known knowns' (the results of a study; certain evidence) and 'known unknowns' (certain variables not researched; certain contexts not taken into account). 'Unknown unknowns' are possible risks, future outcomes, or consequences one is not aware of.

While 'known unknowns' may point to the direction of future research, 'unknown unknowns' point to the fundamental uncertainty in scientific research. By *imagining* possible events and occurrences, certain 'unknown unknowns' may become 'known unknowns.' Similarly, by pointing out certain 'blind spots' in a frame of reference, 'unknown unknowns' may become 'known unknowns,' or even 'known knowns' once they are researched (Box 10.10).

**Q9:** What is the significance of your data?

- What do your findings say in respect to alternative explanations and plausible objections?
- What are the limits of interpretation of your study?

## 10.11 Reporting and Dissemination of Research Findings

### *10.11.1 Dissemination and Responsibility*

Research findings are commonly reported in scientific outlets, such as peer reviewed journals and scholarly books, or at international congresses and academic conferences. Alternative ways to reach various other audiences may include: articles in popular journals and newspapers; brochures and leaflets tageting certain lay audiences; appearances in seminars for professionals; participation in think tank research; radio and television performances; hosting of podcasts; involvement in internet forums; providing training sessions; and individual or group counseling (for further discussion see Oliver 2010).

**Box 10.10: Qualitative Research**

In qualitative research, many of the steps described in this chapter cannot be separated clearly, but rather merge under certain conditions. The following flowchart, borrowed from Damianakis and Woodford (2012, p. 715) details various considerations when planning a research project in small connected communities, recruiting participants, collecting data, and disseminating results (Fig. 10.4).

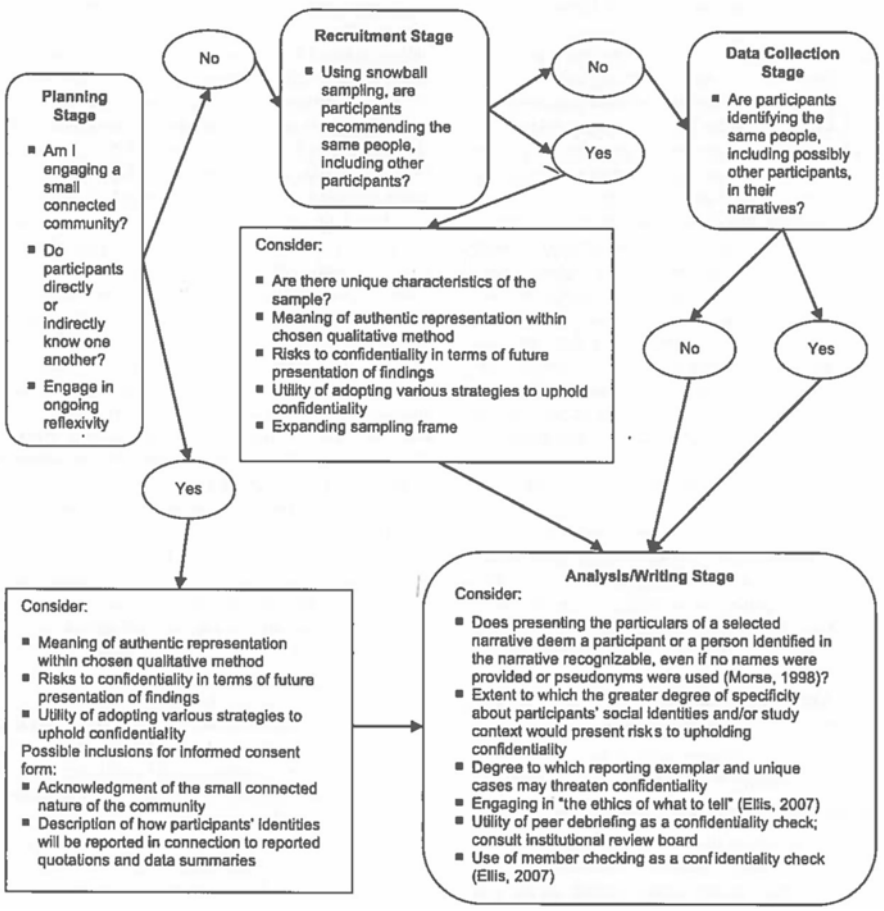


**Fig. 10.4** Considerations when planning a research project (Damianakis and Woodford 2012, p. 715)

We shall not discuss all of these individual forms of communicating research findings, but instead we will flesh out the ethical implications of three different *role responsibilities* (Mitcham 2003) inherent in the task of a researcher engaging with their audiences.

### *10.11.2 Responsibility to Participant*

Researchers carry a responsibility to inform their participants about the results of their work. How do they fulfill this requirement? Often they suffice to just offer the possibility to learn about the findings of their research projects, and this usually entails no more than notifying the participants when the report is published.

In many cases, this may be sufficient, especially when participants have simply filled out a questionnaire or took part in an experiment, and were not otherwise involved in the research project. Considering that oftentimes research participants are not typical readers of academic journals, no further action may be required on the part of the researcher.

However, if, as in qualitative research, or in action research, respondents have dedicated time and energy into research projects, or are involved in it to some degree, the responsibility of the researcher to inform them of their research findings would not end there.

In either case it may be worthwhile to consider how respondents are affected by the research, and whether or not some 'aftercare' is needed in the form of ad hoc reevaluation or debriefing (Box 10.11).

### *10.11.3 Responsibility to the Research Community*

There is also an obligation to communicate research findings to the scientific community, and this obligation goes hand in hand with the requirement to be critical of one another's work in service of furthering scientific knowledge. There are a few issues that can be raised here too.

Academic engagement with private industry is rapidly growing, and this is impacting academic research, as a literature review by Perkman et al. (2013) reveals. Commercialization may enhance productivity (on the short run), but it also impacts the agendas of researchers and promotes an environment of secrecy.

Although research commissioned by third parties is becoming more prevalent, it should be made perfectly clear whose interests are at stake. It has therefore become common practice for researchers to be required to disclose any affiliations with outside institutions; reveal specific financial arrangements, including arrangements concerning intellectual property; as well as divulge any other ties of a social, political, or personal nature that might indicate a conflict of interest. In short, researchers must be hyper-transparent (for further discussion, see Chap. 8).

**Box 10.11: Whose Perspective Prevails?**
Reporting research findings can be precarious, as the following example of an unpublished qualitative study reveals. The research project, financially supported by several municipalities, aimed to analyze the perspectives of policy makers, healthcare providers, and their clients on homeless shelters.

In several interviews, some of the clients (homeless individuals) complained about the poor living conditions in one of the shelters, and the inadequate support offered by one of the healthcare providing parties therein. One interviewee said: 'It's a mess. At least that's how I see it. If you want to help people, you should do it completely different.' Several of these complaints were included in the first report released, which was subsequently sent to the parties involved in the research project, including the healthcare providers.

Shortly thereafter, an argument arose between the researcher and the healthcare provider that had been criticized. The healthcare provider objected to the 'uncritical publication' of these complaints, which they believed were baseless and even harmful.

The researcher offered the healthcare provider an opportunity to contradict the complaints in a separate section, which would be inserted as an addendum in the next report sent to the relevant parties. The healthcare provider declined, insisting that it should be the researcher *themselves* that rectified what they considered to be a 'grave mistake.' The researcher's supposed portrayal of a 'crooked image' of the organization would cause them serious damage, the healthcare provider argued.

The researcher objected, contending that it was their academic duty to report *all* research findings and not to favor one party. The healthcare provider thereupon threatened to file an official complaint against the researcher, with whom they would no longer collaborate if the researcher would not concede.

How would you advise this researcher? Should they:

1. Back down, revise the text, and omit the complaints to rescue the working relationship with the healthcare provider?
2. Persevere as a scientist who has the duty to report findings as objectively as possible, even at the cost of a working relationship?

Which option would you choose, and why?

(Case was communicated to one of the authors of this chapter.)

### *10.11.4 Responsibility to Civic and Professional Communities*

Disseminating knowledge to civic and professional communities entails a different focus than those of academic communities. Inasmuch as sharing knowledge is geared towards the application of theoretical insights, the information provided needs to be of practical value, which can be used for the purpose of training, evaluation, risk assessment, or other needs (Fig. 10.5).


**Fig. 10.5** 'Vaxxed', the 2016 documentary defending Wakefield and his followers

This means a shift away from asking whether research conclusions are true (the focus of academic knowledge dissemination), toward asking under what conditions and assumptions the findings are valid (the focus of civic and professional knowledge dissemination), and this task has a number of ethical implications. This is especially true when vulnerable communities or developing countries are involved and questions of social responsibility emerges. What are the researchers'

obligations towards these communities? Due to their economic, political, and intellectual power, what are the duties of the scientist in relation to society and public interests (Payne, 2000) (Box 10.12)?

**Q10:** Which information are you obliged to share with your research participants?

- Which ties, commitments, and affiliations are of importance to the understanding of your research?
- Which moral responsibilities do you have towards others, specifically to those with a stake in your research?

**Box 10.12: The Anti-Vax Movement. Who is Responsible for What?**

A 1998 paper published in *The Lancet* (a high-ranking peer reviewed medical journal) connecting MMR (Measles, Mumps and Rubella) vaccination and the onset of autism sparked a worldwide anti-vaccination movement, raging still today.

The paper describes twelve children, most of whom were diagnosed with autism, who had bowel and behavioral problems. Eight of those children were purported to have developed autistic symptoms within a few days after they had been given the MMR vaccine. The story was picked up by several large UK newspapers and became the center of a nationwide debate in the subsequent years. This fervor eventually spread to other countries, which brought the paper's principal author, Andrew Wakefield, considerable fame but also substantial criticism.

The scope of the paper was very limited (it was merely a series of 'case reports' and the sample size was only twelve). Based upon scientific norms, it would not have led to any reputable conclusion about a relationship between the MMR vaccination and autism. In fact, subsequent studies failed to find *any* such connection. These later studies, that did systematically probe the relationship between MMR vaccines and autism, received far less media coverage than the original Wakefield paper (see Ben Goldacre's 2009 *Bad Science* for details about the study and its media reception).

*The Lancet* study was retracted when it was found to be seriously flawed on several accounts. Data had been falsified and the research was deemed unethical because of Wakefield's 'callous disregard for any distress or pain the children might suffer.' Additionally, it was argued that the author himself was compromised because of undisclosed financial conflicts of interest. Wakefield's medical license was revoked in 2010.

All of this did nothing to deter the anti-vax movement (of which Wakefield was, and still is, the poster child) or halt its momentum. There was even a 2016 documentary with a pro-Wakefield spin, called *Vaxxed,* which in the tradition of conspiracy theories, was advertised: 'from cover-up to catastrophe.'

The number of people who refuse to vaccine their children has now risen to dangerous levels. These individuals believe, misinformed as they may be, that measles is harmless, vaccines are dangerous, and that the government has

(continued)

**Box 10.12** (continued)

no business interfering in their lives. Even worse, some believe that the government conceals 'the truth' for the sake of a 'powerful medical-industrial complex.' The result of this flood of misinformation? Rates of this deadly disease have begun increasing yet again.

The anti-vax case raises the serious question of who is to blame and for what are they to be blamed. Framed differently, where does a researcher's responsibility begin and where does it end? And when do outside parties begin to share in this responsibility?

How would you define the responsibilities of the following actors in this anti-vax case, with regard to their obligation to communicate scientific findings?

Start with Wakefield, as the Principal Investigator (PI) of the study, who has an obligation to report not only truthfully but also responsibly about his research findings. Given that he honestly believes that MMR vaccines relate to (or even cause the onset of) autism, what responsibilities do you think he has as a scientist to communicate his findings? Is he to be blamed for what some consider a dangerous hoax? And how about the other parties involved in this case? Flesh out the responsibilities of all the parties involved as best as you can.

| Actor | Responsibility |
|---|---|
| Wakefield (as PI of the study) | |
| Editor of *The Lancet* | |
| Editors and journalists of newspapers | |
| Documentary filmmakers | |
| Medical researchers | |
| Governments / authorities | |
| Medical doctors | |
| Anti-vaxxers | |

## 10.12 Data Management and Storage

### *10.12.1 Secure Storage*

Secure storage of research data is at the core of research ethics, especially today, in the age of hacking and data breaches, and is subject to expanding regulation worldwide. It serves two basic purposes: *verification* and *reuse* (for secondary analysis).

At first sight, it may appear desirable to simply preserve all data collected during research and to make it available to any and all researchers, in order to prevent fraud and render science more efficient. However, the issue in preserving research data touches on its confidential nature (see Chap. 7). Additionally, the competing

interests of researchers, research participants, and other stakeholders presents a number of challenges. To deepen the challenge, conflicting database legislation in different countries makes the preservation of all research data near impossible.

Decisions have to be made as to whether or not data will be made available, to *whom* will have access, *how* it will be accessed, *where* it will be stored, and *how long* it will be stored (for an overview of these considerations, see Johnson and Bullock 2009). We will briefly discuss the main aspects of these questions below.

### *10.12.2 Sensitive Data*

Before decisions are made about whether data should be archived and shared, the data's sensitivity should be assessed first. What is deemed 'sensitive' in a legal sense may differ from country to country, though many would agree that any data containing personal information would classify as such. Sensitive data would thus include a participant's identity, information about their ethnicity, gender, political opinions, medical history, sexual orientation, religious background, and philosophical beliefs.

How should researcher's deal with sensitive data? Several strategies have been developed to confront this important issue.

*Anonymization* Data is stripped of its identifying properties by assigning a code to specific pieces of information. For example, the name of the participant is replaced by a number. If a key is preserved that enables re-identification (linking names to number, for example), privacy policy requires that the key be stored separately, and shall not be shared.

Other policies insist, however, that no key be kept at all, and that data collection be anonymized right from the beginning, such that all data effectively becomes anonymous the moment it is collected, and can never be linked to individual participants. This strategy is most fitting for quantitative research practices.

*Pseudonymization* The true identity of the research participant or interviewee is concealed by giving them a pseudonym (an alias) and by changing other identifying details that might make identification possible. This strategy is more commonly practiced in qualitative studies, such as ethnography and case histories.

Some regard pseudonymization as an insufficient guarantee of privacy, as clever detective work may enable the identification of participants. For example, almost all of Freud's patients have since been identified, even though he went to great lengths to hide their identities. Destroying field notes to protect a respondents' privacy might seem to be a solution to this issue, though in practice, it raises questions of its own.

*Co-ownership* In some research practices, respondents define the goals of the research project in close collaboration with the researchers and remain actively involved in other stages of the project, including the interpretation and dissemina-

tion of the results. Typically, this is the case in 'action research' or 'community engaged research' (see Friedman Ross et al. 2009).

By becoming closely involved, research participants become co-owners of the research project, but this often means that the researcher cannot offer the same ethical guarantees concerning confidentiality and anonymity, informed consent, and protection from harm as in other research methodologies (Williamson and Prosser 2002). For example, when school professionals conduct action research, confidentiality will be much more difficult to secure (Nolen and van der Putten 2007).

### *10.12.3 Making Data available to Whom?*

There appears to be a near consensus that data should be archived (if only for reasons of verification). There is dissent, however, over whether secondary researchers or other parties should be allowed access to said archived research data, even after anonymization or pseudonymization.

Large longitudinal research projects almost by definition require the sharing of data, if only for reasons of efficiency. However, legislation in many countries has become much more stringent about protecting the rights of research participants, and this can become an obstacle in these projects.

Legislation safeguards the rights of participants to:

Have access to their own data
Have their data corrected or removed at their request
Refuse any other use of their data than agreed upon

Should the foundational principles of privacy be followed strictly, as some argue, no other researchers should be allowed access to data *unless* participants consent to secondary analysis. Others, however, maintain a more liberal perspective, arguing that if data is entirely anonymized, then these restricting conditions need not apply. But even if that is the case, collaboration between teams of researchers from different countries can become quite difficult given that each country may possess different privacy rules.

### *10.12.4 Storing Data Where?*

Securing data implies storage in a safe place. This could be an encrypted university hard drive, or the implementation of encryption software. Agreements must be made in advance as to who has access, and to which parts of the hard drive. Additionally, the question is who will maintain the data once it is stored.

For security reasons, data should never be kept on personal computers, laptops, or other information carriers. Similarly, hardcopy receptacles of sensitive

information should be kept in safe places, such as a vault or a locker that can opened by designated people only.

Finally, some considerations must be given to possible data breaches, data leakages, and the accidental loss of sensitive data. What are the procedures that must be followed in the event that sensitive information is lost, or even made public by accident? Who needs to be informed, and who has which responsibilities?

### *10.12.5 Archiving Data for How Long?*

Lastly, decisions must be made as to *how long* data should be stored. Some conflicts of interest may arise here. Some universities and research institutions insist on the extended storage of data (at least 10 years) for verification purposes, to prevent fraud and/or uncover forms of misconduct. This requirement, however, conflicts with certain privacy laws, which may demand the destruction of unnecessary data as soon as possible. It may also conflict with contractual obligations made with study participants (for example, when consent to participate in a study is given under the condition that collected data is destroyed immediately after the study report has been published).

**Q11:** How should you ensure that any sensitive data is rendered in a form that is fitting for the research purpose and stored in a safe manner?

- With whom can your data safely be shared?
- What are the data security and safe storage procedures at your institute or university? How do they differ from the agreements you've made with you research participants?
- What is a safe amount of time to archive sensitive data?

## 10.13 Conclusions

### *10.13.1 Summary*

In this chapter, we followed a step by step approach to the ethical questions you need to answer when planning a research project. The objective was to learn what questions to ask, and to reflect on the answers as you plan and design a research project (see Box 10.6).

First, we discussed what research questions must be asked, to consider how important they are, and to think about what your research can contribute to. This was followed by a cost-benefit analysis of the risks inherent to research in the social sciences.

**Fig. 10.6** Ready to submit your research proposal?

Second, we examined the various implications in using a variety of research techniques, including the *invasion of integrity* and the risks of *deception*. We followed this with a brief outline of *informed consent protocols* and how you can avoid harm and do good.

Third, we considered the ethical issues involved in *collecting*, *analyzing*, and *interpreting* data. What (un)intended consequences does your presence in the field have on the participants and research outcomes? What promises do you have to live up to?

Finally, we reviewed the responsibilities that come with being a researcher, specifically when sharing your findings with others. We concluded with a discussion of the various issues involved in safely storing data.

Followed from start to finish, this chapter aimed to ensure social science researchers were made aware of any potential ethical pitfalls that may be encountered. Are you ready now to submit your research proposal? (Fig. 10.6)

**Suggested Reading**

We highly recommend *Research Ethics and Integrity for Social Scientists* (Israel 2015) and *The Student's Guide of Research Ethics* (Oliver 2010) as excellent reference books for students who want to learn more about the principles and philosophies of research ethics. Israel in particular gives an overview of the varying ethical policies found throughout the world. *The Handbook of Social Research Ethics* (edited by Mertens and Ginsberg 2009) offers an excellent selection of essays on a wide variety of topics in the history, theory, philosophy, and implementation of applied social research ethics. Especially worth mentioning is Chap. 8, on IRBs, written by Spiegelman and Spears. *Principles of Biomedical Ethics* (Beauchamp and Childress 2001) is a classic in the field of research ethics. Diener and Crandall's *Ethics in Social and Behavioral Research* (1978) offers an older yet still relevant insight into the field of research ethics as it first emerged.

## 10.14 Ethics Checklist

The following checklist may be useful when designing a research project. It is designed for students who do research under the supervision of a qualified researcher and can be adjusted at will and according to their own needs. It is emphatically not meant to replace local IRB's protocols.

| | |
|---|---|
| **Project details** | |
| Project title | |
| **Applicant details** | |
| Name of student(s) | |
| Email address / student id number | |
| University / department | |
| Course name (if applicable) | |
| Supervisor's name | |
| Duration (from / to) | |
| **Research project** | |
| Please provide a brief outline of your study. What is its **purpose**? What are the main **theoretical assumptions**? What is/are the **research question(s)?** (ca. 200–300 words)<br>Outline:<br>Research questions:<br>Hypotheses: | |
| **Please answer the following questions to the best of your knowledge. Consult supervisor if needed.** | |
| 1. **Participants** | |
| What is the (estimated) number of participants. What is the power analysis to determine sample size, if relevant? | |
| Does the study involve participants who are unable to give informed consent (i.e. people with learning disabilities)? If yes: Explain why and what measures you will take to avoid or minimize harm. | |
| Does the research involve potentially vulnerable groups (i.e. children, people with cognitive impairment, or those in dependent relationships)? If yes: Explain why and what measures you will take to avoid or minimize harm. | |
| Will the study require the cooperation of a gatekeeper for initial access to the groups or individuals to be recruited? (i.e. students at school, members of self- help group, residents of nursing home)? If yes: Who is the gatekeeper? What agreement have you made, and which expectations do you share? | |
| Will it be necessary for participants to take part in the study without their knowledge and consent at the time (i.e. covert observation of people in non-public places)? If yes: Explain why and how, and provide a risk analysis if applicable. | |
| Will any dependent relationships exist between anyone involved in the recruitment pool of potential participants? If yes: Explain why and how, and provide a risk analysis | |
| 2. **Research design and data collection** | |
| Will the study involve the discussion of sensitive topics? (i.e. sexual activity, drug use, politics) if yes: Which topics will be discussed or investigated, and what risk is involved? What measures have you taken to minimize any risk, if applicable? | |

| |
|---|
| Are drugs, placebos, or other substances (i.e. food substances, vitamins) to be administered to the study participants? If yes: Explain the procedure and provide a brief cost-benefit analysis. What measures have you taken to minimize any risk, if applicable? |
| Will the study involve invasive, intrusive, or potentially harmful procedures of any kind? If yes: Explain the procedure and provide a brief cost-benefit analysis. What measures have you taken to minimize any risk, if applicable? |
| Could the study induce psychological stress, discomfort, anxiety, cause harm, or have negative consequences beyond the risks encountered in everyday life? If yes: Clarify the procedure and explain why no alternative method could be used. Provide a brief cost-benefit analysis if necessary. What measures have you taken to minimize any risk, if applicable? |
| Will the study involve prolonged or repetitive testing? If yes: Explain the procedure and clarify how the interests of the participants are safeguarded. |
| Is there any form of deception (misinformation about the goal of the study) involved? If yes: Explain the procedure and provide a rationale for its use. |
| Will you be using methods that allow visual and/or vocal identification of respondents? If so: What will you do to guarantee anonymity and confidentiality? |
| Will you be collecting information through a third party? If yes: Who is that party? Provide a brief outline of the procedure. |
| Will the research involve respondents on the internet? If yes: How do you plan to anonymize the participants? |
| How will you guarantee anonymity and confidentiality? Outline your procedure and give an estimate of the risk of a breach of confidentiality. |
| What information in the informed consent will participants be given about the research? Provide a brief summary or upload the consent form. Which procedures are in place in case participants which to file a complaint? |
| Will financial compensation will be offered to participants? Provide a short accounting of any compensation being offered. |
| If your research changes, how will consent be renegotiated? |
| 3. **Analysis and interpretation** |
| What is the expected outcome of your research? What would you consider a significant result? |
| During the course of research, how will unforeseen or adverse events be managed (i.e., do you have procedures in place to deal with concerning disclosures from vulnerable participants)? |
| 4. **Dissemination** |
| How do you plan to share your research findings? Which audience to you intend to target? |
| 5. **Data storage** |
| Where will your data be stored? Which measures have you taken to make sure it is secure? |
| Which safety precautions have you arranged for in case of data leakage? |
| Will your data be disposed of? If yes: When? (date) if no: Why not? |
| Will your research involve the sharing of data or confidential information beyond the initial consent given (such as with other parties)? What specific arrangement have you made and with whom? |
| **Principal investigator / teacher** |
| Signed: Date: Place: |
| **Student** |
| Signed: Date: Place: |

## 10.15 Sample Informed Consent Form

[Adapt this form to your proposed research project].

Information about Participation in a Research Study at [your university or research institute]

[Title of the study:]

INTRODUCTION: Thank you for taking part in this study about [give brief explanation of the study]. Below is a description of the research procedures and an explanation of your rights as a research participant. In accordance with the ethics code of the [local institution], you are asked to read this information carefully. You are entitled to receive a copy of this form should you agree to proceed under the terms stated.

GENERAL INFORMATION: The purpose of this research is [give brief description of study purpose here]. This research is funded by [insert here, if applcable]. The potential conflicts of interest are [describe any that are known]. [OR] There are no known conflicts of interest in the conducting of this research study.

Your participation will last for approximately [duration estimate] and will take place at [location] at the following times [dates/times]. You will receive [insert reimbursement, i.e.. number of PPU, amount of money, a chance to win a voucher or, 'no reimbursement'] for your participation in this study.

PROCEDURE: During this study, you will be asked to [insert brief description of what the participant will do]. You are aware that [describe any risks that are known]. [OR] There are no known or anticipated risks associated with participation in this study.

You have the right to end your participation at any moment, without citing a reason. If you choose to end your participation before the study terminates, you [will / will not] be reimbursed.

Regarding the use of your data, the following conditions apply:

- Your data will be used for scientific purposes, including publication. Only the researchers have access to the data [OR] The data will be made available for other researchers on condition of confidentiality.
- Your data will be handled and stored confidentially. This means that your data cannot be traced back to you. Specifically, the researcher will use a code number instead of your name to save your data.
- [If the data from the study will be personally identifiable] The code number and other personally identifiable information, such as names, will be saved separately from each other in a secure location.
- After publication, only the data that is necessary for the verification of the study results will be kept and stored safely for a minimum of 10 years and deleted once it is no longer needed. [OR] Personally identifiable data will be shared only if it is scientifically required to verify reported results.
- You have the right to withhold any responses you have provided from subsequent analysis. This means we will not use your data for this or any follow-up research, nor will we share it anonymously for open science purposes. You can decide to

withdraw your data until the study results are accepted for publication, or until the data is cleared of any and all identifying information, such that no-one will be able to trace you.

OFFER TO ANSWER QUESTIONS: You are now given the opportunity to ask questions. If you have any further questions or complaints about this study, you may contact the researcher, [name(s) of researcher(s) and email(s)—phone number(s) can be added if researchers prefer to use that method], of [your university or research institute].

## References


Appelbaum, P. S., Roth, L. H., Lidz, C. W., Benson, P., & Winslade, W. (1987). False hopes and best data: Consent to research and the therapeutic misconception. *Hastings Center Report, 17*(2), 20–24. https://doi.org/10.2307/3562038.

Anderson, E. E. (2019). A proposal for fair compensation for research participants. *The American Journal of Bioethics, 19*(9), 62–64. https://doi.org/10.1080/15265161.2019.1630501.

Baumrind, D. (1964). Some thoughts of ethics of research: After reading Milgram's study of obedience. *American Psychologist, 19*(6), 421–423. https://psycnet.apa.org/doi/10.1037/h0040128.

Beauchamp, T. L., & Childress, J. F. (2001). *Principles of biomedical ethics*. Oxford: Oxford University Press.

Beck, H. P., Levinson, S., & Irons, G. (2009). Finding little Albert: A journey to John B. Watson's infant laboratory. *American Psychologist, 64*(7), 605–614. https://psycnet.apa.org/doi/10.1037/a0017234.

Becker-Blease, K. A., & Freyd, J. J. (2006). Research participants telling the truth about their lives: The ethics of asking and not asking about abuse. *American Psychologist, 61*(3), 218–226. https://doi.org/10.1037/0003-066X.61.3.218

Benatar, S. R. (2002). Reflections and recommendations on research ethics in developing countries. *Social Science & Medicine, 54*(7), 1131–1141. https://doi.org/10.1016/S0277-9536(01)00327-6.

Bracken-Roche, D., Bell, E., Macdonald, M. E., & Racine, E. (2017). The concept of 'vulnerability' in research ethics: An in-depth analysis of policies and guidelines. *Health Research Policy and Systems, 15*(1), 8. https://doi.org/10.1186/s12961-016-0164-6.

Brotsky, S. R., & Giles, D. (2007). Inside the "pro-ana" community: A covert online participant observation. *Eating Disorders: The Journal of Treatment & Prevention, 15*(2), 93–109. https://doi.org/10.1080/10640260701190600.

Burbules, N. (2009). Privacy and new technologies. In D. M. Mertens & P. E. Ginsberg (Eds.), *The handbook of social research ethics* (pp. 537–549). London: Sage.

Castellano, M. B. (2014). Ethics of aboriginal research. In W. Teary, J. S. Gordon, & A. D. Renteln (Eds.), *Global bioethics and human rights. Contemporary issues* (pp. 273–288). Lanham: Rowman & Littlefield.

Christensen, L. (1988). Deception in psychological research: When is its use justified? *Personality and Social Psychology Bulletin, 14*(4), 664–675.

Cohen, J. J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). Hillsdale: Erlbaum.

Cromer, L. D., Freyd, J. J., & Binder, A. K. (2006). What's the risk in asking? Participant reaction to trauma history questions compared with reaction to other personal questions. *Ethics and Behavior, 16*(4), 347–362. https://doi.org/10.1207/s15327019eb1604_5.

Damianakis, T., & Woodford, M. R. (2012). Qualitative research with small connected communities: Generating new knowledge while upholding research ethics. *Qualitative Health Research*. https://doi.org/10.1016/j.fsigen.2012.10.002.

DePrince, A. P., & Freyd, J. J. (2006). Costs and benefits of being asked about trauma history. *Journal of Trauma Practice, 3*(4), 23–35. https://doi.org/10.1300/J189v03n04_02.

Diener, E., & Crandall, R. (1978). *Ethics in social and behavioral research*. Oxford: University of Chicago Press.

Douglas, H. (2014). Values in Social Science. In N. Cartwright & E. Montuschi (Eds.), *Philosophy of the social sciences. A new introduction* (pp. 162–184). Oxford: Oxford University Press.

Elam, G., & Fenton, K. A. (2003). Researching sensitive issues and ethnicity: Lessons from sexual health. *Ethnicity and Health, 8*(1), 15–27. https://doi.org/10.1080/13557850303557.

Ellis, C. (2014). Telling secrets, revealing lives. Relational ethics in research with intimate others. *Qualitative Inquiry, 19*(1), 3–29. https://doi.org/10.1177/2F1077800406294947.

Eysenbach, G., & Till, J. E. (2001). Ethical issues in qualitative research on internet communities. *British Medical Journal, 323*(7321), 1103–1105. https://doi.org/10.1136/bmj.323.7321.1103.

Friedman Ross, L., Loup, A., Nelson, R. M., Botkin, J. R., Smith, G. R., & Gehler, S. (2009). The challenges of collaboration for academic and community partners in a research partnership: Points to consider. *Journal of Empirical Research on Human Research Ethics, 5*(1), 19–31. https://doi.org/10.1525/2Fjer.2010.5.1.19.

Goffman, A. (2014). *On the run: Fugitive life in an American city*. Chicago: University of Chicago Press.

Goldacre, B. (2009). *Bad science*. London: Fourth Estate.

Guillemin, M., & Gillam, L. (2004). Ethics, reflexivity, and "ethically important moments" in research. *Qualitative Inquiry, 10*(2), 261–280. https://doi.org/10.1177/2F1077800403262360.

Haggerty, D. C. (2004). Ethics creep: Governing social science research in the name of ethics. *Qualitative Sociology, 27*(4), 391–414.

Heinrich, J., Heine, S. J., & Norenzayan, A. (2010). The weirdest people in the world? *Behavioral and Brain Sciences, 33*(2–3), 61–83. https://doi.org/10.1017/S0140525X0999152X.

Hey, J. D. (1998). Experimental economics and deception: A comment. *Journal of Economic Psychology, 19*, 397–401.

Hjortskov, N., Rissén, D., Blangsted, A. K., et al. (2004). The effect of mental stress on heart rate variability and blood pressure during computer work. *European Journal of Applied Physiology, 92*, 84–89. https://doi.org/10.1007/s00421-004-1055-z.

Hughes, J. (ed.) (2010). European Textbook on Ethics in Research. Brussels, European Union Directorate-General for Research.

Illes, J., Kirschen, M. P., Edwards, E., Stanford, L. R., Bandettini, P., Cho, M. K., Ford, P. J., Glover, G. H., Kulynych, J., Macklin, R., Michael, D. B., Wolf, S. M., et al. (2006). Incidental findings in brain imaging research. *Science, 311*, 783–784. https://doi.org/10.1126/science.1124665.

Israel, M. (2015). *Research ethics and integrity for social scientists* (2nd ed.). London: Sage.

Johnson, D., & Bullock, M. (2009). The ethics of data archiving: Issues from four perspectives. In D. Mertens & P. Ginsberg (Eds.), *The handbook of social research ethics* (pp. 214–228). London: Sage.

Khanlou, N., Koh, J. G., & Mill, C. (2008). Cultural identity and experiences of prejudice and discrimination of Afghan and Iranian immigrant youth. *International Journal of Mental Health and Addiction, 6*(4), 494–513. https://doi.org/10.1007/s11469-008-9151-7.

Kimmel, A. J. (1998). In defense of deception. *American Psychologist, 53*, 803–805. https://psycnet.apa.org/doi/10.1037/0003-066X.53.7.803.

Lawson, E. (2001). Informational and relational meanings of deception: Implications for deception methods in research. *Ethics & Behavior, 11*(2), 115–130. https://doi.org/10.1207/S15327019EB1102_1.

Liang, B., & Lu, H. (2006). Conducting fieldwork in China: Observations on collecting primary data regarding crime, law, and the criminal justice system. *Journal of Contemporary Criminal Justice, 22*(2), 157–172. https://doi.org/10.1177/2F1043986206286918.

Lubet, S. (2015). Ethics on the run. *The New Rambler Review*, May, 15–34. https://ssrn.com/abstract=2611742

Mark, M. M., & Lanz-Watson, A. L. (2011). Experiments and quasi-experiments in field settings. In A. T. Panter & S. K. Sterba (Eds.), *Handbook of ethics in quantitative evaluation* (pp. 185–209). New York: Routledge.

Marshall, R. D., Spitzer, R. L., Vaughan, R., Mellman, L. A., MacKinon, R. A., & Roose, S. P. (2001). Assessing the subjective experience of being a participant in psychiatric research. *American Journal of Psychiatry, 158*, 319–321.

McAreavey, R., & Das, C. (2013). A delicate balancing act: Negotiating with gatekeepers for ethical research when researching minority communities. *International Journal of Qualitative Methods, 12*(1), 113–131. https://doi.org/10.1177/2F160940691301200102.

Mertens, D., & Ginsberg, P. E. (Eds.). (2009). *The handbook of social research ethics*. London: Sage.

Mikesell, L., Bromley, E., & Khodyakov, D. (2013). Ethical community-engaged research: A literature review. *American Journal of Public Health, 103*(12), e7–e14. https://doi.org/10.2105/AJPH.2013.301605.

Miller, F. G., Mello, M. M., & Joffe, S. (2008). Incidental findings in human subjects research: What do investigators owe research participants? *Journal of Law, Medicine & Ethics, 36*(2), 271–279. https://doi.org/10.1111/j.1748-720X.2008.00269.x.

Mitcham, C. (2003). Co-responsibility for research integrity. *Science and Engineering Ethics, 9*(2), 273–290. https://doi.org/10.1007/s11948-003-0014-0.

Mustanski, B. (2011). Ethical and regulatory issues with conducting sexuality research with LGBT adolescents: A call to action for a scientifically informed approach. *Archives of Sexual Behavior, 40*(4), 673–686. https://doi.org/10.1007/s10508-011-9745-1.

Newman, E., Walker, E. A., & Gefland, A. (1999). Assessing the ethical costs and benefits of trauma-focused research. *Law, Ethics, and Psychiatry in the General Hospital, 21*(3), 187–196.

Nie, J. B. (2001). Is informed consent not applicable in China? Intellectual flaws of the "cultural difference argument". *Formosan Journal of Medical Humanities, 2*(1–2), 67–74.

Nolen, A. L., & van der Putten, J. (2007). Action research in education: Addressing gaps in ethical principles and practices. *Educational Researcher, 36*(7), 401–407. https://doi.org/10.3102/2F0013189X07309629.

Numan, D., & Di Domenico, M. L. (2012). Market research and the ethics of big data. *International Journal of Market Research, 55*(4), 505–520. https://doi.org/10.2501/2FIJMR-2013-015.

O'Reilly, M., & Parker, N. (2012). 'Unsatisfactory saturation': A critical exploration of the notion of saturated sample sizes in qualitative research. *Qualitative Research, 13*(2), 190–197. https://doi.org/10.1177/2F1468794112446106.

Oliver, P. (2010). *The student's guide to research ethics* (2nd ed.). Berkshire: Open University Press.

Ortmann, A., & Hertwig, R. (2002). The costs of deception: Evidence from psychology. *Experimental Economics, 5*, 111–131. https://doi.org/10.1023/A:1020365204768.

Parker, L., London, A. J., & Aronson, J. D. (2012). Incidental findings in the use of DNA to identify human remains: An ethical assessment. *Forensic Science International Genetics, 7*(2), 221–229. https://doi.org/10.1016/j.fsigen.2012.10.002.

Payne, S. L. (2000). Challenges for research ethics and moral knowledge construction in the applied social sciences. *Journal of Business Ethics, 26*(4), 307–318. https://doi.org/10.1023/A:1006173106143.

Perkman, M., Tartari, V., McKelvey, M., Autio, E., Broström, A., D'Esti, P., Fini, R., Geuna, A., Grimaldi, R., Hughes, A., Krabel, S., Kitson, M., Lierena, P., Lissoni, F., Salder, A., & Sobrero, M. (2013). Academic engagement and commercialization: A review of the literature on university-industry relations. *Research Policy, 42*(2), 423–442. https://doi.org/10.1016/j.respol.2012.09.007.

Ran, M. S., Ziang, M. Z., Chan, C. L. W., Leff, J., Simpson, P., Huang, M. S., Shan, Y. H., & Li, S. G. (2003). Effectiveness of psychoeducational intervention for rural Chinese families experiencing schizophrenia. *Social Psychiatry and Psychiatric Epidemiology, 38*(2), 69–75. https://doi.org/10.1007/s00127-003-0601-z.

Rangle, L., Embry, T., & MacLeon, T. (2001). Active and passive consent: A comparison of actual research with children. *Ethical Human Sciences and Services, 3*(1), 23–31. https://doi.org/10.1891/1523-150X.3.1.23.

Schenk, K. D., & RamaRao, S. (2016). Ethical considerations of conducting research among children and young people affected by HIV: A view from an ethics review board. In P. Liamputtong (Ed.), *Children and young people living with HIV/AIDS: A cross-cultural perspective* (pp. 445–457). Cham: Springer.

Schneider, C. (2015). *The censor's hand: The misregulation of human-subject research*. Cambridge: The MIT Press.

Scott, A. (2017). *My IRB nightmare. Slate Star Codex*. Retrieved March 17, 2020, from http://slatestarcodex.com/2017/08/29/my-irb-nightmare/#comments

Szala-Meneok, K. (2009). Ethical research with older adults. In D. M. Mertens & P. E. Ginsberg (Eds.), *The handbook of social research ethics* (pp. 507–517). London: Sage.

Tangwa, G. B. (2014). Ethics, human rights, and sexual/reproductive health in Africa: Exploratory sociocultural considerations. In W. Teary, J. S. Gordon, & A. D. Renteln (Eds.), *Global bioethics and human rights: Contemporary issues* (pp. 160–173). Lanham: Rowman & Littlefield.

Tolich, M. (2014). What can Milgram and Zimbardo teach ethics committees and qualitative researchers about minimizing harm? *Research Ethics, 10*(2), 86–96. https://doi.org/10.1177/2F1747016114523771.

Van Bommel, M., van Prooijen, J.-W., Elffers, H., & van Lange, P. A. M. (2014). Intervene to be seen: The power of a camera in attenuating the bystander effect. *Social Psychological and Personality Science, 5*(4), 459–466. https://doi.org/10.1177/1948550613507958.

Vargas, L. A., & Montaya, M. E. (2009). Involving minors in research. In D. M. Mertens & P. E. Ginsberg (Eds.), *The handbook of social research ethics* (pp. 489–509). London: Sage.

Vernooij, M. W., Arfan Ikram, M., Tanghe, H. L., Vincent, A. J. P. E., Hofman, A., Krestin, G. P., Niessen, W. J., Breteler, M. M. B., & van der Lugt, A. (2007). Incidental findings on brain MRI in the general population. *The New England Journal of Medicine, 358*(18), 1821–1828. https://doi.org/10.1056/NEJMoa070972.

Williamson, G. R., & Prosser, S. (2002). Action research: Politics, ethics and participation. *Journal of Advanced Nursing, 40*(5), 587–593. https://doi.org/10.1046/j.1365-2648.2002.02416.x.