FORS GUIDES
to survey methods
and data management

Ethics in the era of open research data: some points of reference

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FORS Guide No. 03, Version 1.0

January 2019

Abstract:

This document provides points of reference for researchers seeking to manage their data in the most ethical way possible in the era of open research data. Through a presentation of binding and non-binding regulatory frameworks, it addresses some points to be taken into account in order to make data as open as possible while ensuring an adequate level of protection.

Keywords: data management, ethics, regulations, data protection

How to cite:

Diaz, P. (2019). *Ethics in the era of open research data: some points of reference*. FORS Guide No. 03, Version 1.0. Lausanne: Swiss Centre of Expertise in the Social Sciences FORS. doi:10.24449/FG-2019-00003

The FORS Guides to survey methods and data management

The FORS Guides offer support to researchers and students in social sciences, who intend to collect data, as well as to teachers at University level, who want to teach their students the basics of survey methods and data management. Written by experts from inside and outside of FORS, the FORS Guides are descriptive papers that summarise practical knowledge concerning survey methods and data management. The FORS Guides go beyond the documentation of specific surveys or data management tools and address general topics of survey methodology. They give a general overview without claiming to be exhaustive. Considering the Swiss context, the FORS Guides can be especially helpful for researchers working in Switzerland or with Swiss data.

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1. INTRODUCTION

In recent years, the normative frameworks that underpin social science research have undergone significant transformations. Among the most important changes is the increasing pressure to share research data. Since 2018, the Swiss National Science Foundation (SNSF) has required all its funded researchers "to store the research data they have worked on and produced during the course of their research work, to share these data with other researchers (…) and to deposit their data and metadata onto existing public repositories in formats that anyone can find, access and reuse without restriction"[1]. In parallel with this development, there has been a strengthening of ethical and legal regulatory frameworks for data protection. At European level, the entry into force of the General Data Protection Regulation (GDPR) has significantly strengthened the rights for individuals whose personal data are is processed. The tensions generated by these contradictory movements are not easy to resolve. The purpose of this guide is to provide points of reference for researchers seeking to manage their data in the most ethical way possible in the era of open research data.[2]

2. OPEN RESEARCH DATA IS NOT A RIGID FRAMEWORK

The new data management policies of research funding institutions have sparked considerable debate around the world. In England, for example, the "perceived injunction to archive data has been met with resistance by recalcitrant researchers who are wary of the implications of depositing data, and the possibilities of reusing data" (Moore, 2007). The greatest resistance has come from researchers working with methods derived from anthropology, for whom fieldnotes generally have an intensely private nature:

> "The people being observed forget you're there. There is something unethical about that: they go on about their business, and you're still observing. So to have fieldnotes that reflect your direct observations become public property is (…) a betrayal of trust" (Jackson, 1990, p. 22).

It is, however, important to reassure researchers about the latitude they still have in terms of data openness. Sharing data partially, conditionally or even not at all, is possible as the new regulatory framework provides for many exceptions. For example, the SNSF fully recognises that "some data cannot be shared because applicants are bound by legal, ethical, copyright, confidentiality or other clauses". In such cases, however, researchers are required to "explain their specific constraints".[3] It is, therefore, useful to understand the open research data paradigm as an opportunity to better justify and reflect on research practices rather than as a directive to the reckless application of top-down standards.

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[1] http://www.snf.ch/en/theSNSF/research-policies/open_research_data/Pages/default.aspx#SNSF%20policy%20on%20Open%20Research%20Data

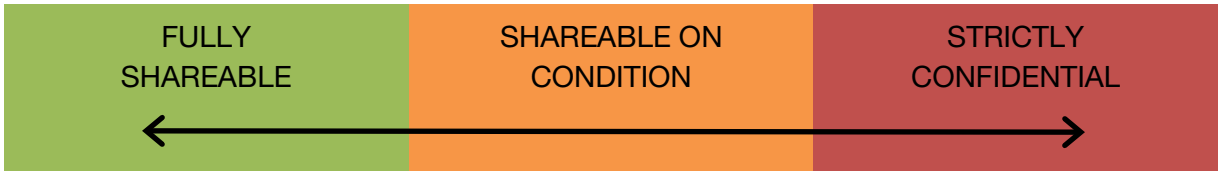
[2] We would like to thank Marta Roca i Escoda and Claudine Burton-Jeangros for their careful review of this guide and their wise advice.

[3] http://www.snf.ch/en/theSNSF/research-policies/open_research_data/Pages/default.aspx#SNSF%20policy%20on%20Open%20Research%20Data

2.1 OPENNESS AS A CONTINUUM

The notion of "data openness" tends to confuse researchers regarding how and to what extent they must make their materials available to others. It is, therefore, important to clarify what is expected/allowed or not in terms of data sharing. More than an impulsion to make all data public, the open research data framework is an invitation to make data as open as possible depending on their nature (public, personal, sensitive, protected by copyright, classified, etc.). Thus, if according to the "libertarian" ideal data are public good that should be available to all, reality is significantly more complex. This is why it is useful to think more in terms of a "shareability" continuum.[4] Simply put, this continuum ranges from fully shareable data to strictly confidential data (for an illustration see figure 1). Between these two extremes, the data can only be shared under certain conditions. Fully shareable data may be public data or low-risk data for which researchers have obtained comprehensive informed consent. Strictly confidential data may be classified data or high-risk data for which it is impossible to obtain consent. Conditionally shareable data may be medium-risk data for which consent can be obtained and which may be subject to more or less extensive anonymisation.

Figure 1: Data shareability continuum



In the following sections, we will focus on different ethical considerations – not exhaustive – to take into account when processing data. The idea is to draw the attention of researchers to the necessary trade-offs to make data as open as possible while ensuring an adequate level of protection.

3. RESEARCH ETHICS STANDARDS

Research ethics is governed by various more or less restrictive rules, which include, among others, laws, charters, guides, codes, good practices, and personal convictions. Among these different standards, it is useful to distinguish between those that are legal and those that are strictly speaking "ethical" (for an illustration see figure 2).

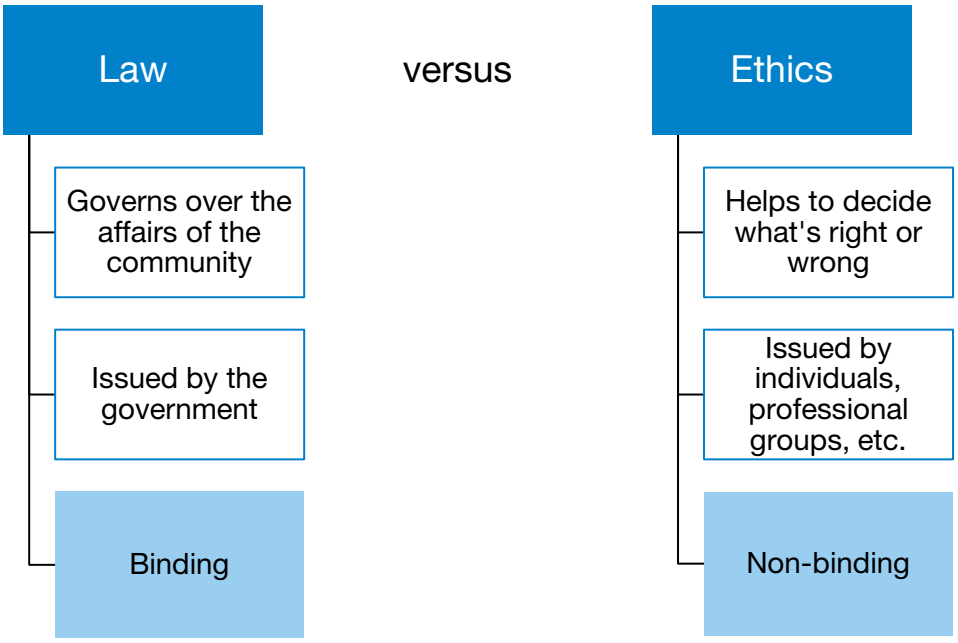
In simple terms, the law refers to a set of rules put in place by the ruling authority to govern over the affairs of the community.[5] These rules are determined by a legal system and an explicit system of sanctions. Ethics, on the other hand, refer to morally-based principles of conduct that define what is right or wrong to do independently of or beyond our strictly legal

[4] In a similar vein, the Open Data Institute (ODI) refers to a Data Spectrum: https://theodi.org/about-the-odi/the-data-spectrum/

[5] http://www.differencebetween.info/difference-between-law-and-ethics, retrieved October 18, 2018

obligations (Dubreuil, 2011). This distinction is essential in the sense that “an action may be legal but unethical or illegal but ethical”.[6]

Figure 2: main differences between legal and ethical standards



Is compliance with the law an ethical guarantee? Feedback from the field

As part of FORS’ data management assistance mission, we were confronted with complex situations where compliance with procedures – particularly legal procedures – did not appear to be ethically sufficient.

This is, for example, the case for research involving political activists in authoritarian contexts. Some researchers have expressed their discomfort when faced with members of the political opposition who wanted their testimonies to be quoted non-anonymously – for political reasons. The physical and moral risks incurred by these people make it ill-advised to satisfy this desire. Thus, even when a person gives consent to use his or her data openly, it is not necessarily ethical to do so. Compliance with procedures – legal or otherwise – does not exempt the researcher from an ad-hoc ethics assessment.

3.1 NON-BINDING STANDARDS

In Switzerland, at the non-binding level, there is no global consensus on what constitutes ethical research practice. The Swiss Academies of Arts and Sciences published basic principles of scientific integrity (Académie Suisse des Sciences, 2008), but these remain very general and focus mainly on issues of truthfulness, transparency and intellectual honesty. More specifically, the document defends the establishment of binding regulations to address incorrect behaviour in the scientific community in terms of "violation of confidentiality or intellectual property, usurpation of authorship, unfair interference with scientific activity, retaliation against so-called ‘whistleblowers’, and incitement to fraud and its concealment" (p. 10). However, not all disciplinary associations have gone through a

[6] https://www.niehs.nih.gov/research/resources/bioethics/whatis/, retrieved October 18, 2018

process of formalizing their ethical principles. Researchers, therefore, do not always find formal guidelines to help them. In the following sections, we will offer an overview of the different resources and reflections made available by the professional associations representing the fields of psychology, sociology, ethnology, and political science – often little known to the community itself.[7]

Psychology

Due to its proximity to the biomedical field and the common use of experimental methods, psychology is one of the most highly regulated fields in terms of ethics. Research activities in psychology are governed by the Code of Ethics of the Swiss Society of Psychology. The duties of the psychology researcher are formulated as follows (Société Suisse de Psychologie, 2003):

- Methodological competence (Art. D12 to D14);
- Respect for the willingness of individuals to participate or not in research (Art. D15, Art. D18) or to withdraw at any time (Art. D22);
- The duty to explicitly inform research participants before the start of the study (Art. D16) or, in certain strictly defined cases – when deception is necessary for research purposes and when expected benefits are considered to exceed the risks and constraints for the participant – at the end of the data collection (Art. D20 to D22);
- The obligation to obtain explicit consent from the participants, in particular in the case of sound or video recording (Art. D17 and D19), except in the case where the data are anonymised during processing or if a higher authority explicitly allows it;
- The duty to propose and implement measures to limit, reduce or mitigate to a minimum the possible side effects and damage that the research may have on participants (Art. D18, D19 and D25).

In summary, research ethics in psychology places particular emphasis on the issues of participant information, consent and protection. It is a relatively strict framework that closely follows the legislation on research on human beings (see section 3.2) and makes the integrity and dignity of participants its central principles.

Sociology

In 2007, the Swiss Society of Sociology (SSS) proposed to its members the adoption of an ethical charter aimed at providing ethical principles and rules governing the professional practice of sociologists. Drafted on the basis of the ethical code of the German Sociological Society and the Professional Association of German Sociologists, this document was structured around the principles of scientific integrity, informed consent of participants, the duty of confidentiality with regard to the data collected, and the limitation of harms incurred as a result of participation in research. Among the most salient points were (Société suisse de sociologie, 2007) :

[7] This part benefited is largely inspired by an internal report from the University of Lausanne, carried out by Nathanaëlle Minard.

- The importance of taking into account the social influence of sociological work and preventing "any misuse" of it (Art. I, 1)
- The need to take "adequate measures to ensure that research does not limit or exclude, in the future, access to the study population for other members of the profession" (Art. I, 7)
- The respect for the rights of individuals (Art. I, 8)
- The "detailed" information of participants on the objectives and methods of the project and the obligation to justify "in detail" any legitimate reservation to this duty (Art. I, 9)
- Preserving the anonymity of participants and ensuring their protection. Participants must not "suffer harm or danger as a result of the research" (Art. I, 10)
- The duty to prevent potential breaches of confidentiality by using "protocols that exclude the identification of the persons studied and ensure the protection of confidential information" (Art. I, 12)

However, this draft ethical charter has never been approved by SSS members. While they readily recognise the importance of ethics concerns, Swiss sociologists wonder about the need to create rules that are additional to the existing legal framework, as well as the possibility of reaching unanimity on these questions (Société suisse de sociologie, 2008, p. 12-13). Consequently, the SSS has aligned itself with the principles of scientific integrity proposed by the Swiss Academies of Sciences, which, in its view, are sufficient with a "clear focus on the main issues and (...) adopt a clear position on the legal aspects" (Société suisse de sociologie, 2009, p. 10). From their point of view, new professional standards could hinder sociological research, for example by encouraging researchers to favour certain fields and avoid others (such as very closed environments or institutions to which the researcher could have difficulty having access if he/she clearly states the subject of his/her research at the beginning of the study), or to favour certain methods – to the detriment, for example, of secret observation, which should, according to the draft SSS ethical charter, be systematically justified in detail (as provided for in Article I, 9).

Ethnology

The Swiss Society of Ethnology (SSE) officially took a similar stance as the SSS: "the adoption of a charter was considered too prescriptive and reflecting a particularly defensive position" (Société Suisse d'Ethnologie, 2011, p. 2). The SSE has therefore chosen to provide a number of avenues for ethical reflection in the form of a position paper.

The SSE is very critical on the concept of "informed consent" – derived from clinical or experimental practices – that, in its view, does not adapt well to the realities in the field of ethnologists (SSE, 2011, p. 4). For SSE, consent cannot be obtained ex-ante once and for all but should be negotiated "throughout the research process", taking into account not only particular local situations and interactions with respondents but also the conduct of the research with its unexpected turns, unknowns, and reversals.

In its position paper, the SSE also addresses the ethical issues related to the collection and dissemination of personal, identifying, and sometimes sensitive data. Establishing as a fundamental ethical principle of ethnological research "the respect and protection of the

researcher's interlocutors in the field", it proposes several ways to reconcile this concern with the realities of the ethnographic process (SSE, 2011, pp. 7-8):

- Give respondents the opportunity to take a position on the interpretations and conclusions of the research, and take these reactions and feedback into account when publishing the results;
- Consult respondents before publishing the results in order to avoid certain critical situations related to the difficulty of maintaining true anonymity in social contexts of high inter-knowledge and or ambiguity in the relationship between the researcher and respondents in the field.

Political science

Political science has one of the oldest formalised relationship to ethics in the Swiss social sciences. Already in 1995 the Swiss Political Science Association (SPSA) adopted a code of ethics, inspired by the Code of the German Political Science Association. The document emphasised – among others – the duty to guarantee freedom of decision with regard to participation in a research project as well as the need to treat with special attention individuals with "low professional qualifications, low social status or belonging to a minority or marginal groups" (Association suisse de science politique, 1995). It also invited political scientists to respect "professional secrecy" and to refuse to "testify, when there is a reason to fear that the sources (the informants) may risk sanctions (especially criminal ones)" (SPSA, 1995).

In 2011, this code was replaced by the principles of integrity of the Swiss Academies of Sciences (Association Suisse de science politique, 2011). The latter was considered to be more in line with the new investigation methodologies used in political science – experimentation, observation, etc. – as well as with the Federal Act on Research on Human Beings. This decision is nevertheless surprising since the document provided by the Swiss Academies of Sciences is much more general than the old SPSA code with regard to the protection of participants and the duties of researchers in this respect.

A look abroad

To conclude this brief overview of the non-binding framework of research ethics, it is important to stress that many resources can be found at the international level. Thus, while some Swiss professional/disciplinary associations do not have ethical charters, their counterparts in other countries may have some. In Anglo-Saxon countries, professional associations in the social sciences have more or less detailed ethical codes that can be useful for guidance about what may constitute appropriate behaviour for the different disciplines – although it is true that standards can vary widely from one geographical context to another. For example, the American Political Science Association[8], the American Sociological Association[9] and the American Anthropological Association[10] have quite extensive ethical codes. In addition, the scientific literature increasingly tends to invest in the field of ethics through practical feedback from the field (see for example Burton-

[8] https://www.apsanet.org/portals/54/Files/Publications/APSAEthicsGuide2012.pdf, retrieved October 18, 2018
[9] http://www.asanet.org/sites/default/files/asa_code_of_ethics-june2018.pdf, retrieved October 18, 2018
[10] http://ethics.americananthro.org/category/statement/, retrieved October 18, 2018

Jeangros, 2017). These various writings constitute a broader and more flexible framework, which may be complementary or an alternative to a national framework.

3.2 BINDING STANDARDS

While they must be distinguished, law and ethics are closely linked. Indeed, not only do both constitute sets of norms, but also the law often formalises moral rules. It is therefore not surprising that a number of ethical principles are enshrined in law. In this section, we will focus on the existing legal framework in order to define the outlines of the rights and obligations of researchers and research participants. More specifically, we will focus on the ethical considerations provided by laws that relate to research on human beings and those that relate to data protection. The idea is to provide a general – and not exhaustive – picture of the legal framework in order to make researchers aware of the main things to consider when conducting a research project. This presentation does not, in any way, exempt researchers from carefully reading the laws or resorting – when necessary – to proper legal expertise.

Federal Act on Research on *Human* Beings

The Swiss Federal Act on Research on Human Beings (Human Research Act, HRA) is the law that governs "research on human diseases and on the structure and functioning of the human body" (Art. 2). Completed and clarified by the Ordinance on Human Research with the Exception of Clinical Trials (HRO), its scope of application is "any project for which biological material is collected from a person or personal data related to his or her health are collected in order to respond to a scientific problem or to reuse biological material or health-related data for research purposes" (Art. 6). The objectives of the HRA are to "protect the dignity, personality and health of the human being in research", while aiming to "create conditions favourable to research on human beings and to "contribute to ensuring the quality and transparency of research on human beings" (Art. 1).

The implementation of the HRA is largely decentralised. This law requires that any research project that falls within its scope must be evaluated by the ethics committee of the canton in whose territory the research is conducted (Art. 32, Art. 47). All researchers working on subjects related to the disease, structure and functioning of the human body, or at least those working with personal data related to these subjects should, therefore, consult their cantonal commission to determine whether or not they are subject to the HRA. If so, they must submit their project for evaluation before any data is collected.

The HRA was designed to apply primarily to research in the biomedical field. However, it also extends to social science research involving the collection of personal/sensitive data related to health. While the decisions of the cantonal ethics commissions are sometimes contradictory regarding the scope of application of the HRA, it is possible to provide some examples of projects potentially subject to it:

- research involving the consultation of medical records or the collection of personal data from populations suffering from diseases, disabilities, or at the end of life (e.g. the study of children's experiences of chronic diseases, the analysis of the family relationships of hospice residents with Alzheimer's disease, etc.)
- research involving observations in hospitals or care centres;

- sexual health surveys
- research on the causes of psychological disorders such as depression

It is important to note that the HRA does not apply to research carried out on data that has been collected anonymously or anonymised – in both primary and secondary analysis.

The HRA and HRO have important consequences on the research process as they require the informed and explicit consent of participants as a precondition for research involving human beings: « Persons may only be involved in a research project if they have given their informed consent. Consent must be given in writing » (HRA, Art. 16). In addition, the persons concerned must receive comprehensible oral and written information on (HRA, Art. 16):

- the nature, purpose, and duration of, and procedure for, the research project;
- the foreseeable risks and burdens;
- the expected benefits of the research project, in particular for themselves or for other people;
- the measures taken to protect the personal data collected; and
- their rights.

and on (HRO, Art.8):

- the effort involved and the obligations arising from participation;
- their right to withhold or to revoke their consent without giving reasons;
- the consequences of revoking consent to further use of the biological material and personal data collected up to this point;
- their right to receive information at any time in response to further questions;
- their right to be informed of results concerning their health, and their right to forgo such information or to designate a person who is to take this decision for them;
- the measures envisaged to cover any damage arising from the research project, including the procedure in the event of a claim;
- the main sources of financing for the research project;
- other points relevant to their decision on participation.

Procedures and modalities of consent, however, vary according to the risks entailed by the data collection methods. More precisely, projects considered “low risk” (category A), such as those based on observation and questionnaires benefit from a lighter informed consent system:

- the information may be given to the participants in successive stages and in a form other than the text (HRO, Art. 8);
- consent may be given and documented in a form other than written form (oral consent), provided that the research project is carried out with adults capable of discernment (Art. 9);
- the possibility of using personal health-related data even after the revocation of consent, provided that the data are anonymised (Art. 10).

Despite these exceptions, researchers are never exempt from the obligation to inform participants in advance of the conditions and objectives of the project (Art. 8), and to guarantee the protection of personal data collected and/or used (Art. 5).

HRA and HRO also provide for reuse of personal health data. According to HRA, reuse of non-anonymised data must always be subject to consent: "If the intention exists to make further use for research of biological material sampled or health-related personal data collected, the consent of the persons concerned must be obtained at the time of such sampling or collection, or they must be informed of their right to dissent" (Art. 17). Researchers subject to this law must, therefore, provide – where possible – in their consent protocols for the archiving and reuse of collected materials if they wish to meet the requirements of open research data. When planning to reuse health data, researchers must provide the following information to the data subjects (HRO, Art. 24):

- the proposed further use of the non-genetic health-related personal data for research purposes;
- their right to withhold or to revoke their consent at any time without giving reasons;
- their right to be informed of results concerning their health, and their right to forgo such information;
- measures to protect the personal data;
- the possibility of the personal data being passed on to third parties for research purposes.

The Federal Data Protection Act (DPA)

The Federal Data Protection Act (DPA) legally defines the central concepts of "personal data" and "sensitive data" (Art. 4). Personal data is defined as all information that relates to an identified or identifiable person.

Sensitive data are personal data that relate to:

- "religious, philosophical, political or trade union opinions, activities and ethnic origin;
- the intimate sphere of the person, in particular, his psychological, mental or physical state;
- individual measures and aid resulting from social legislation;
- criminal and administrative proceedings or sanctions".

Personal data constitute a particular type of data in the sense that their processing requires "the consent of the data subject". Moreover, "consent must be given expressly in the case of processing of sensitive personal data or personality profile" (Art. 4). The term "processing" contains any operation with personal data, irrespective of the means applied and the procedure, and in particular the collection, storage, use, revision, disclosure, archiving, or destruction of data.

While consent is presented as mandatory for personal data processing, it is important to note that research is subject to a number of special legal provisions. The HPA provides, for example, that "a breach of privacy is unlawful unless it is justified by the consent of the injured party, by an overriding private or public interest or by law". Processing personal data

"for purposes other than those relating to individuals, in particular in the context of research, planning or statistics" is specifically considered as an overriding interest (Art. 13). However, researchers must always comply with the following conditions (Art. 22):

- "the data is rendered anonymous, as soon as the purpose of the processing permits
- the results are published in such a manner that the data subjects may not be identified".

It is important to note that the Federal Data Protection Act is supplemented by cantonal laws – to which universities are subject. It is therefore essential for researchers to examine the legal regime to which they are subject.

4. RESEARCH ETHICS, A MATTER OF ARBITRATION: SOME REFLEXIONS

While it is important to know the normative framework, ethics is above all a matter of practice. Indeed, far from being confined to a "set of values and principles", ethics is "a reasoned reflection with a view to doing the right thing".[11] Doing research in an ethical way thus, implies a number of trade-offs and compromises. More precisely, it is a question of finding a balance between what research demands, the duty of protection, and institutional requirements.

In the following sections we will reflexively approach the practical trade-offs posed by three of the main ethical principles: free and informed consent; respect for privacy and confidentiality; and "do no harm". The aim is to show that seriously taking ethics is above all a reflexive process rather than a question of systematically applying rules.

4.1 FREE AND INFORMED CONSENT

In Switzerland, the informed consent of participants is legally required to process personal and or sensitive data. Anyone wishing to analyse or archive and share non-anonymised personal/sensitive data must, therefore, ensure that individuals have freely and properly given their consent. Although justified, this measure raises a number of problems, paradoxically ethical.

The historical reason for the legal requirement to obtain the consent of participants is to ensure that they participate freely and consciously in the investigation. In practice, it has, however, gradually become a legal protection tool for researchers. The tightening of data protection laws, coupled with the increase in legal proceedings against researchers (for defamation, invasion of privacy, etc.), have largely distorted the original purpose of consent (Laurens & Neyrat, 2010). In a context where participants are increasingly seen as potential "threats", consent is seen more as a means of attesting to the researcher's good faith than a genuine ethical concern. In order to restore the ethical nature of consent, it is therefore essential to put the interests of participants back at the centre of the reflexion.

[11] http://www.ethique.gouv.qc.ca/fr/ethique/quest-ce-que-lethique/quelle-est-la-difference-entre-ethique-et-morale.html

In addition, ethics is increasingly codified and formalised, which runs counter to its dynamic nature. Excessive formalism can contribute to reducing ethics to its most procedural conception, thus diverting attention from its content. The question of free and informed consent is illustrative in this regard. The requirement to have complex and detailed consent forms signed may give the illusion that one of the fundamental ethical principles has been met, even though participants have not necessarily understood the scope and consequences of their participation. The very notion of "informed" consent is problematic because participants are often unable to appreciate what scientific work is all about and, therefore, what they are engaging in (Roselli, 2011; Marchive, 2012; Sommier & Torreiro, 2010). The same applies to the notion of "freedom" since "by virtue of characteristics associated with age or disability, an individual can be rendered relatively powerless in exercising free will when choosing whether or not to serve as a research participant" (Drew, Hardman, & Hosp, 2008). Taking ethics seriously into account, therefore, requires reflection on the truly "informed" and "free" nature of consent.

There may be cases where the informed consent of participants may prove to be an obstacle to the research process. Some approaches are, for example, crossed by the "suspicion that the disclosure of the identity of the sociologist would bias the collection of data or even prevent the conduct of the investigation and therefore access to the data. Informed consent on the part of the persons or groups surveyed is therefore absent" (Genard & Roca i Escoda, 2010, p. 147). Some disciplines – such as psychology – have therefore formalised the possibility of "deception" for the good of the research project. The Swiss Society of Psychology's code of ethics states, for example, that while researchers must always inform participants about the research project, they may nevertheless "cheat" if the deception is "necessary for research purposes" or if "the expected benefit is considered to exceed the risks and constraints for the experimental subject". The American Sociological Association code of ethics provides also for the use of deception techniques when "(1) the research involves no more than minimal risk to research participants; (2) deception is justified by the study's prospective scientific, educational, or applied value; (3) equally effective alternative procedures that do not use deception are not feasible; and (4) they have obtained the approval of an authoritative body with expertise on the ethics of social science research such as an institutional review board" (American Sociological Association, 2018, paragraph 11.4).

Although it is at the heart of ethics, the issue of consent cannot be limited to an automatic reflex or administrative constraint. On the contrary, it must give rise to genuine reflection and is always a matter of balance and compromise. The aim is to minimize the risks for participants while maximizing the benefits for the research project.[12] This compromise must take into account the particularities of the field of research, the approach adopted, the ethical standards in force in the researcher's discipline, and the legal framework. In the end, whatever strategy is finally adopted, it must always be justified (for more information see also FORS Guide No.05 "The informed consent as legal and ethical basis of research data production").

4.2 RESPECT FOR PRIVACY AND CONFIDENTIALITY

[12] http://www.inf.ed.ac.uk/teaching/courses/hci/1617/lects/Lecture08_ethics.pdf

Many ethical standards make anonymity a fundamental principle when processing personal/sensitive data. Respect for privacy – and therefore confidentiality – is at the heart of many practices and regulations. In addition, many researchers are accustomed to systematically, if not automatically, promising anonymity to participants. As Niamh Moore points out: "Anonymity is a key concern of much social research, often deemed essential, a self-evident principle for protecting research participants from possible harm" (2012, p. 332).

However, the issue of anonymisation polarises debates considerably. Not only are there discussions about the "impoverishing" impact that anonymisation can have on materials, but also the relationship to confidentiality varies widely across disciplines, methods, and objects. Researchers who conduct sample surveys are, for example, used to anonymising their datasets. One reason for this is that this type of research is less about producing in-depth knowledge on a small number of cases than about producing general knowledge on aggregate data (Tsai et al., 2016). Researchers who work with ethnographic methods are also committed to anonymisation, which they often consider as being an "ethical imperative" (Roux, 2010). On the other hand, researchers adopting historical perspectives seem much more reluctant to anonymise their materials: "The historian, in view of the requirements of his discipline, needs the testimony to be made public, accessible, identified, verified and controlled. The more the testimony is exploited, the more it is used publicly and by name, the better" (Müller, 2006, p. 108). Some oral historians such as Paul Thompson – a pioneer in oral history – have gone further by making naming a genuine ethical issue: "The idea of giving voice to the informants was always important, giving them the opportunity to be heard under their own names rather than being automatically cited anonymously" (2008, p. 41).

In view of these few considerations, it is clear that the ethical issue of anonymity is complex and contextual. It is therefore essential to take into account disciplinary, contextual, and epistemological factors when setting up a research confidentiality policy.

4.3 "DO NO HARM"

Last but not least, the principle we would like to address is that of "do no harm". In the context of research ethics, harm can be defined "to include extreme physical pain or death, but also involves such factors as psychological stress, personal embarrassment or humiliation, or myriad influences that may adversely affect the participants in a significant way" (Drew et al., 2008, p. 64). That is an important principle because it refers to one of the fundamental mechanisms of research ethics: risk assessment. Indeed, as Denis Harrisson (2000, p. 39) points out "ethical judgment is based on balancing the consequences of the research process for human subjects with the benefits and risks to subjects assessment". It is, therefore, essential for the researcher to assess the potential risks that he or she poses to participants when conducting the research, which involves asking oneself questions, such as:

- What kind of impacts can the presence of the researcher in the field have on his informants?
- What reputational, psychological and or physical effects might the publication of data have on the participants?

- How can these effects be controlled in order to achieve mutual respect between the researcher and the respondents? (Weber, 2008)

There are no easy answers to these questions. However, it is essential for the researcher to reflect on them, especially since the risks can vary considerably from one situation to another. There are, in fact, subjects, populations, and fields that are more sensitive than others. Working on restricted networks of knowledge or public figures does not pose the same problems as working on large "anonymous" populations. While there are no ready-made procedures to follow, it is possible to point out that it is essential not to adopt an overly formal approach to protecting respondents. There are cases where, despite compliance with procedures, a number of risks persist. In these cases, it is up to the researcher to assess the situation and ultimately decide whether or not to make this kinds of material public. In other words: "Consent, even under the most careful precautions, does not render an investigator free to ignore further responsibility regarding potential harm" (Drew et al., 2008, p. 65).

In addition, it is important to note that some devices intended to protect respondents end up having the opposite effect. That is particularly the case for the destruction of materials. The case of Alice Goffman and her book "On The Run" (2014) is interesting in this regard. Indeed, in order to protect her informants – namely criminals on the run – Alice Goffman burned all of her field notes. Apart from the strong scientific controversies that this gesture raised – particularly on the transparency of her approach – the fact of making its materials inaccessible largely pushed journalists to want to find her informants. Some researchers have seen this as an opportunity to warn the "would-be data incinerators" of the unexpected effects of this type of practice: "While Alice Goffman's motivation to protect her Philadelphian interlocutors was certainly admirable, the way she went about it seems to have caused a lot of negative scrutiny of her work and, most unfortunately, not a lot of protection in the end" (Kirilova & Karcher, 2017, p. 5).

At this point, it is important to recall the fact that – as we have pointed out above – if ethics is a question of risk assessment, it is also a question of benefit assessment. There are therefore cases where the social benefits may be considered higher than the risks involved. Scientific activity is, in fact, a public good primarily associated with the idea of progress. The risks involved must, therefore, always be balanced against the potential benefits of research – in terms of knowledge, improved policies, denunciation of inequalities, etc. To illustrate this point, Drew et al. use the example of a research project that could solve the US inflation problem: "to conduct the study, a sample of 1,000 participants would be required to divulge personal details concerning amount and sources of income, as well as the manner in which every dollar was spent. Certainly, this represents a substantial invasion of privacy – but there is also a dire need to solve the inflation problem" (2008, p. 65). Even though the question of whether the benefits exceed the costs is a matter of personal judgment, the authors strongly advise referring to an expert external to the research project.

5. IMPLICATIONS FOR RESEARCHERS

The ethics of social science research is not an easy question. The disciplinary, epistemological, and geographical differences are significant, and the debates are lively. It is, therefore, not possible - or even counterproductive – to provide fixed principles.

However, with a few general recommendations, it is possible to ensure researchers consider ethics in their projects:

Recommendation 1 – Researchers should be aware of the different regulatory frameworks that apply to their field of research and institutional settings (law, disciplinary ethical codes, university charters, etc.)

Recommendation 2 – Researchers should ensure that consent is truly free and informed. To do this, the respondent's interests must be put first – unless the social benefits outweigh the risks involved.

Recommendation 3 – Researchers should conduct a risk assessment for any project, even when the consent of the participants has been obtained.

Recommendation 4 – Researchers should seek advice from their universities or relevant ethics commissions as soon as they are in doubt about the ethical implications of their research projects.

Recommendation 5 – Researchers should be aware that ethical issues are deeply practical and should, therefore, avoid excessive formalism.

Recommendation 6 – Researchers should communicate more about the ethical issues of their research projects in order to enrich the literature on the subject and create more collective knowledge.

FURTHER READINGS AND USEFUL WEB LINKS

For a comprehensive introduction to ethics in the social sciences, we recommend reading the Mertens and Ginsberg handbook (2009). On the issues specific to qualitative methods we recommend that of Miller, Birch, Mauthner, and Jessop (2012), and on quantitative methods that of Panter and Sterba (2011).

Examples of codes and ethical charters in Switzerland:

- University of Geneva: https://www.unige.ch/ethique/files/5014/8844/4831/CharteEthique-105x210-2017-WebEN.pdf
- Code of Research Ethics for Universities of Teacher Education : https://www.hepl.ch/files/live/sites/systemsite/files/centre-soutien-recherche-relations-internationales/pole-levees-fonds/code-ethique-recherche-rd-2002-hep-vaud.pdf
- Checklist for the ethical evaluation of research projects in psychology (Swiss Society of Psychology) :

  French: https://swisspsychologicalsociety.ch/sites/default/files/public/pdf/Checklist_09%2005%2007_f_d.pdf

  German: https://swisspsychologicalsociety.ch/sites/default/files/public/pdf/ersgp2003.pdf

REFERENCES

American Sociological Association (2018), Code of ethics, Retrieved October, 18, 2018, from http://www.asanet.org/sites/default/files/asa_code_of_ethics-june2018.pdf

Association suisse de science politique (2011), Procès-Verbal de l'assemblée générale de l'ASSP du 13 janvier 2011, Retrieved October 18, 2018, from https://www.svpw-assp.ch/en/the-association/general-assembly/protocols/

Association suisse de science politique (1995), Code d'éthique de l'Association suisse de science politique (ASSP), adopté à Berne le 11 octobre 1995

Burton-Jeangros, C. (2017), L'éthique (en) pratique: la recherche en sciences sociales. *Genève: Université de Genève*. Retrieved October 18, 2018, from http://archive-ouverte.unige.ch/unige:99839

Drew, C. J., Hardman, M. L. & Hosp, J. L. (2008). *Designing and conducting research in education*. Los Angeles, London, New Dehli, Singapore: Sage Publications.

Dubreuil, B. (2011). Réguler l'éthique par le droit. *Kleis – Revue philosophique*, 21, 78-111.

Genard, J. L., & Roca i Escoda, M. (2010). La "rupture épistémologique" du chercheur au prix de la trahison des acteurs ? Les tensions entre postures "objectivante" et "participante" dans l'enquête sociologique. *¡Ethique publique*, 12, 139-163.

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

Harrisson, D. (2000). L'éthique et la recherche sociale. In Karsenti, T.and Savoie-Zajc, L. (Eds). *Introduction à la recherche en éducation*. Sherbrooke : CRP.

Jackson, J. E. (1990). "I Am a fieldnote": Fieldnotes as a symbol of professional identity. In Sanjek, R. (Ed.). *Fieldnotes: The Makings of Anthropology* (pp. 3-33). Ithaca and London: Cornell U Press.

Kirilova, D., & Karcher, S. (2017). Rethinking data sharing and human participant protection in social science research: Applications from the qualitative realm. *Data Science Journal*, 16, 1-7

Laurens, S., & Neyrat, F. (Eds.) (2010). *Enquêter de quel droit ? Menaces sur l'enquête en sciences sociales*. Paris: Editions du Croquant.

Marchive, A. (2012). Contrôle et autocensure dans l'enquête ethnographique. Pour une éthique minimaliste. *Les Sciences de l'éducation – Pour l'Ère nouvele, 2012,* 45, 74-94.

Mertens D. M. & Ginsberg P. E. (2009). *The handbook of social research ethics.* Thousand Oaks, CA: SAGE Publication.

Miller, T., Birch, M., Mauthner, M., & Jessop, J. (Eds.) (2012), *Ethics in qualitative research*, London UK: Sage

Moore, N. (2007). (Re)Using qualitative data? *Sociological Research Online*, *12*, 1-13.

Moore, N. (2012). The politics and ethics of naming: questioning anonymisation in (archival) research. *International Journal of Social Research Methodology*, 15, 331-340.

Müller, B. (2006). Archives orales et entretiens ethnographiques. Un débat entre Florence Descamps et Florence Weber, animé par Bertrand Müller. *Genèses*, 62, 93-109.

Panter, A. T., & Sterba, S. K. (Eds.) (2011), *Handbook of ethics in quantitative methodology*, New-York: Sage

Roselli, M. (2011). Pourquoi restituer n'est pas (seulement) communiquer. Retour critique sur deux échecs. *Revue ¿Interrogations ?*, 13, [online], Retrieved October, 18, 2018 from http://www.revue-interrogations.org/Pourquoi-restituer-n-est-pas

Roux, S. (2010). La transparence du voile. Critique de l'anonymisation comme impératif déontologique. In Laurens, S. and Neyrat, F. (Eds.). *Enquêter de quel droit ? Menaces sur l'enquête en sciences sociales*. Paris Editions du Croquant.

Société Suisse d'Ethnologie (2011). Une charte éthique pour les ethnologues ? Prise de *position de la SSE*. Retrieved October, 18, 2018, from http://www.seg-sse.ch/pdf/GRED_Prise_de_position_de_la_SSE.pdf

Société Suisse de Psychologie (2003). *Code déontologique.* Retrieved October, 18, 2018, from https://swisspsychologicalsociety.ch/sites/default/files/public/pdf/Code_deontologique.pdf.

Société Suisse de Sociologie (2007). « Ethique de la pratique sociologique ». *Bulletin de la Société suisse de sociologie,* 132. Retrieved October, 18, 2018, from https://www.sgs-sss.ch/wp-content/uploads/2016/04/Bulletin_132.pdf.

Société Suisse de Sociologie (2008). Bulletin 133. Retrieved October 18, 2018, from https://www.sgs-sss.ch/wp-content/uploads/2016/04/Bulletin_132.pdf.

Société Suisse de Sociologie (2009). Bulletin 135. Retrieved October 18, 2018, from https://www.sgs-sss.ch/wp-content/uploads/2016/04/Bulletin_132.pdf.

Sommier, I., & Torreiro, J. J. (2010). Écriture sociologique et labellisation politique : réflexions autour d'un procès en diffamation. In Laurens, S. and Neyrat, F. (Eds.). *Enquêter de quel droit ? Menaces sur l'enquête en sciences sociales*. Editions du Croquant.

Thompson, P. (2008). Pioneering the life story method. In Harrison, B. (Ed.). *Life Story Research*. London, UK: Sage.

Tsai, A. C., Kohrt, B. A., Matthewam, L. T., Betancourt, T. S., Lee, J. K., Papachristos, A. V., … Dworkin, S. L. (2016). Promises and pitfalls of data sharing in qualitative research, *Social Science & Medecine*, 169, 191-198.

Weber, F. (2008). Publier des cas ethnographiques : analyse sociologique, réputation et image de soi des enquêtés. *Genèses*, 70, 140-150.