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# SEARCHING FOR ETHICS

## Legal requirements and empirical issues for anthropology

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### Abstract

This paper analyses the new legal provisions impacting qualitative research practices and contributing to the institutionalization of research ethics in Switzerland. After contextualizing the emergence of new forms of research regulation, it shows how their epistemological assumptions challenge anthropology. It then explores the issues related to the articulation between *procedural ethics* and *processual ethics*. Finally, it discusses the different postures which might possibly be adopted by scholars in anthropology and other qualitative social sciences.

**Keywords:** *research ethics, legislation, informed consent, ethics committees, epistemology*

The Ethical and Deontological Think Tank (EDTT)<sup>1</sup> of the Swiss Anthropological Association (SAA)<sup>2</sup> was established towards the end of 2008 in response to debates about the inclusion in the Swiss Federal Constitution of a new article aiming to strengthen the legal framework covering «research on human beings». It sets itself the task of exploring the impact on the research practices of anthropologists of the introduction of a legal framework to be implemented by cantonal ethics committees. The group produced an initial paper in 2010, with the title *An ethical charter for ethnologists? Proposed ethical position of the Swiss Anthropological Association* (Berthod et al. 2010, transl.),

published in issue 15 of *Tsantsa, The Journal of the Swiss Anthropological Association*. The paper aimed to identify the principal ethical challenges linked to ethnographic engagement, making it possible to «reconcile the epistemological specificities of the ethnological approach, its scientific rigour and its responsibility towards research participants» (*op. cit.*: 150, transl.). It proposed a number of areas for reflection on the emerging institutional arrangements regulating informed consent; on confidentiality, anonymity and the return of results to research participants; as well as on the communication of results to researchers working in the same areas or in teaching<sup>3</sup>. The group subsequently

<sup>1</sup> For information on EDTT, see: <http://www.sagw.ch/en/seg/commissions/commission-scientifique/GRED.html>.

<sup>2</sup> Since February 2016, Swiss Anthropological Association is the official translation of Société Suisse d'Ethnologie. Please note that in previous EDTT documents, the translation Swiss Ethnological Society (SES) was used.

<sup>3</sup> The proposed ethical position was adopted by members of the SAA at its General Assembly in 2010. The ethical position is available online in French, German and English (SAA 2011).

edited and published several *Ethical case studies in ethnological research*, written by anthropologists to analyse and comment on concrete experiences<sup>4</sup>. It also (co)-organized several scientific meetings to encourage group discussion<sup>5</sup>.

## Introduction

The last decade has seen a significant strengthening of the framework covering the social relationships between participants in scientific research and researchers. The extended scope reflects both increased State intervention in the protection of the dignity, privacy and health of research participants and the establishment, on an increasingly transnational basis, of new scientific standards, supported by public bodies responsible for funding research. At the heart of these processes is a collective will to ensure compliance with «good research practice» through the implementation of administrative procedures formalizing the relationships between participants and researchers.

However, it must be recognized that *procedural ethics* (Felices-Luna 2016) – *i.e.* administrative actions based on legal requirements and aiming to protect participants in advance by means of the application of standardized ethical protocols – are not the same as the *processual ethics* applied in the qualitative social sciences. By *processual ethics* we mean approaches which refer to a comprehensive, relational and positional understanding of research ethics<sup>6</sup> and which adapt their prin-

ciples to the specifics of each research site. There is a consensus in anthropology that in practice, any system of moral norms includes contradictions and dilemmas and that consequently ethics – *i.e.* arbitrating between different normative orders – involves «an adjustment of moral choices depending on contexts and circumstances» (Massé 2016, transl.), that is «an equilibrium to be achieved between the various parties involved» (Felices-Luna 2016: 18, transl.).

This paper brings up to date and develops collaborative work carried out over nearly ten years by members of the EDTT (see preamble). It pursues two objectives. It aims to inform social scientists using qualitative methods<sup>7</sup> about recent changes to Swiss legislation on research ethics, while taking account of reorganizations and the directions which some provisions could take in the near future. Observing that anthropologists have not participated in the current political debates about the new legal requirements, it also aims to promote dialogue on research ethics both within the discipline and with other ones. Our analysis of the various laws regulating research shows that the formalization of the relationship between participants and researchers through a «free prior and informed consent» form is becoming a general requirement. This trend calls into question not only the conditions for the production of anthropological knowledge (in particular, access to funding, field locations and publication in scientific journals) but also whether the epistemological and methodological assumptions specific to anthropology, and other qualitative sciences, are taken into account in public debate relating to the role(s) of science in society and research policies.

<sup>4</sup> These ethical case studies tackle a range of ethical issues, such as those relating to restrictions on access in the field (Lavanchy 2012), private funding for research (Leins 2012), consent to research for persons presenting with a lack of mental capacity (Petitpierre et al. 2013), self-censorship (Madec 2013) and the political role of the researcher (Charmillot 2016). They are all available in digital form on the SAA website (<http://www.sagw.ch/en/seg/commissions/commission-scientifique/GRED.html>), and on the website of *Tsantsa, the Journal of the Swiss Anthropological Association* (<http://www.tsantsa.ch/en/edtt/ethic-discussions>).

<sup>5</sup> At the SAA annual conference in 2016, the EDTT brought together researchers from different disciplines (anthropology, sociology, bioethics and medical law) at the round table «Searching for ethics: Legal and relational frameworks of research». In 2017, it co-organized a round table on «Ethics in practice: the researcher's perspective», with FORS, the Swiss national centre of expertise in the social sciences. In the same year, the EDTT organized a module on «Ethics and anthropological research» as part of the Swiss Graduate Program in Anthropology, to offer PhD students the opportunity to discuss the ethical challenges they face. We are grateful to the SAA, the Swiss Academy of Humanities and Social Sciences (SASH) and the *Conférence Universitaire de Suisse Occidentale* (CUSO) who have supported the work of the EDTT through financial contributions to the organization of these meetings and events.

<sup>6</sup> Since the 1990s, the corpus of anthropological literature has become substantially richer and, with it, the definitions of ethics. In this paper, we will use the definition proposed by Raymond Massé: «Ethics [is] a space for questioning whether norms are well-founded, or even for an arbitrage undertaken by individuals and groups between the different norms offered by the multiplicity of moral systems (religious, institutional, community etc.) to which they are exposed. [...] It assumes that the individual is aware of the alternatives and has the critical distance necessary for dissent or informed acceptance. In this sense, it is based on the freedom to analyse and make a judgement.» (Massé 2016, transl.)

<sup>7</sup> This paper is addressed to all researchers, teachers and students engaged in an ethnological activity. The terms «ethnologist» and «anthropologist» are used as synonyms.

This paper<sup>8</sup> is based on analysis of legislative texts and parliamentary debates, enriched by a range of informal interviews with members of the SAA, staff of Swiss federal and cantonal administrations and colleagues from other disciplines. The first part sets out a number of key developments which have contributed to the emergence of *procedural ethics* (section «From the emergence of new ethical sensitivities to their institutionalization»). It then analyses the changes brought about by the inclusion of Article 118b «Research on Human Beings» in the Swiss Federal Constitution (section «Uncertainty as to the scope of the new HRA»), as well as the reorganization of cantonal ethics committees and the resulting responses of the institutional players (section «Reorganization of cantonal ethics committees and institutional responses»). Finally, describing the issues relating to the complete overhaul of the Federal Act on Data Protection (FADP) currently in progress and the completed revision of the Federal Act on the Promotion of Research and Innovation (RIPA, standing for Research and Innovation Promotion Act), it investigates the way in which consent is becoming a central question at the intersection between law, ethics and epistemology (section «Alignment with European standards and institutionalization of restrictive norms: the revisions to the FADP and RIPA»). The second part of the paper focuses on the tensions between *procedural ethics* and *processual ethics*. It first highlights how anthropological debate has contributed to the inclusion of power relations between participants and researchers in the analysis (section «Field relations, power relations?»), and then sets out the conditions for scientific knowledge said to be ethical from the perspective of our discipline (section «Ethical science, good science?»). Finally, noting that anthropologists have not contributed to political debates on the new legal requirements, it discusses three possible positions that might be taken in response to the formalization of the relationships between

participants and researchers required by certain legal provisions through a «free prior and informed consent» form (section «Moralism, pragmatism and dialogue: postures and alternatives»).

## Plurality and changes of normative orders

### From the emergence of new ethical sensitivities to their institutionalization

Since the end of the Second World War, and following the public disclosure of various scandals, scientific research has been the subject of a series of interventions led by professional associations, by universities, and by States<sup>9</sup>. Reflecting increasingly acute sensitivities as to research ethics, voices were raised both within and outside the academic environment, denouncing scientific practices considered to be «unfair» «dishonest» or «bad», or even to be «harmful» and «dangerous». This gave rise to the ethical codes of the professional associations and other university charters, which aimed to regulate the practices of their members through the adoption of guiding principles.

During the 1990s, the development of accountability and audit regimes also helped to reinforce the framework for research by requiring researchers both to deliver a transparent account of their practices and to avoid creating risks that would be borne by the institutions to which they belonged (Amit 2000, Strathern 2000, Boden et al. 2009, Jacob et al. 2007, Lederman 2006a). Among the various measures taken, it is appropriate to highlight the importance of Institutional Review Boards (IRB), which were first developed in the English-speaking world and subsequently spread to other countries. These committees are responsible for assessing research proposals on paper before the

<sup>8</sup> We are very grateful to all those who agreed to share information with us for their stimulating reflections on recent developments in legal frameworks relating to research ethics. This paper has also benefited from the valuable comments of Claudine Burton-Jeangros, Professor of sociology and member of the University of Geneva Research Ethics Board (*Commission universitaire d'éthique de la recherche*), and of Anne Lavanchy, Professor of anthropology at the University of Applied Sciences and Arts for Social Work in Geneva. We deeply thank them for their careful readings of a previous version of this article. We also warmly thank Andreas von Känel (Institute of Anthropology, University of Neuchâtel) for his precious advice on English editing. We nevertheless remain entirely responsible for the limitations of this paper.

<sup>9</sup> The revelation, in 1947, of the experiments carried out by Nazi doctors on people in concentration camps constituted one of the first scandals that led to the development of the Nuremberg Code in 1947. The Tuskegee experiment, carried out between 1930 and 1972, studied nearly 400 African-American men suffering from syphilis, withholding treatment with penicillin, which was discovered in 1947. Their doctors were complicit. This experiment was one of a number of medical scandals in the United States that contributed to the drafting of the Helsinki Declaration by the World Medical Association in 1964 and later to the Belmont Report by the US government in 1978 (see, for example, Lederman 2006a). All these documents state that the interests of the subject should have priority over the interests of society. It should be noted that, as far as we are aware, the revelation of experiments carried out on prisoners in the military bacteriological research unit of the Imperial Japanese Army between 1932 and 1945 does not appear to have played any particular role in the development of codes. In the case of anthropology, the use of anthropologists by the US administration during the Vietnam War was condemned by the American Anthropological Association and gave impetus to the introduction of the first ethical code adopted by the Association, in 1971. The introduction of the code did not however, put an end to debate (see, for example, Assayag 2008).



start of the project, with the aim of protecting participants as well as funding and research institutions, and of checking that ethical principles are respected.

Interestingly, Daniel Cefaï and Paul Costey (2009) note that principles laid down by IRBs are similar in essence to those contained in the Nuremberg Code: (1) respect for individuals as autonomous agents, particularly individuals considered to be vulnerable, who have a right to increased protection (minors and people in a vulnerable position because of social disadvantage, stigma, mental incapacity or disability); (2) care for research participants, which implies that research should not be carried out if it could cause harm to the individuals involved without delivering results of benefit to all the communities in scope; (3) fairness, which requires that research participants should be selected in a way that does not unfairly disadvantage groups that could benefit from the research. Following these principles, IRBs ensure that the protection afforded to research participants is sufficient (in particular, anonymity and protection of personal data) and that the value of the research is established (taking account of its objectives, methodology and procedures).

While the application of the protocols to be followed seems to be straightforward for hypothetico-deductive approaches involving set questions, defined timing and a predetermined sample of participants (Lederman 2007, cited in Fassin 2008: 132), this is more delicate for anthropological research, in which questions evolve as the research progresses and results are generalized by reference to delimited data sets. As noted by many writers on anthropology (Plankey-Videla 2012, Murphy et al. 2007, Shannon 2007, Hammersley 2006, Wax 1980), the requirement for «informed consent», which is at the heart of the *procedural ethics* of IRBs, is problematic when this research approach is adopted.

It can, certainly, be readily accepted that the requirement for «informed consent» could be applied without too much difficulty to the conduct of semi-structured interviews. However, the organization of predetermined samples is not always possible as anthropologists do not always know in advance with whom they will conduct interviews (Dequierez et al. 2013). Moreover, the requirement for signature of a consent form can lead to distrust among interview participants, although the establishment of a relationship of trust, sometimes patiently constructed over time, is fundamental to the work of the ethnographer. It should also

be noted that research protocols submitted to IRBs do not take account of informal interview situations – which may amount to simple «conversations» (Olivier de Sardan 1995) – during which anthropologists arrive at an understanding of a great deal of data produced during their observations. Compliance with the requirement for systematic informed consent is therefore difficult in research conducted by participant observation, even when the role of the anthropologist is clearly understood and has been negotiated in advance with the institutions and groups under study. As highlighted by Rena Lederman, this difficulty has two dimensions: the informality of some field situations, that is «the undemarcated moments of ethnographic practice when «research» and «daily life» are inextricable» (2006a: 477); and participant observation, the specificity of which is to «plac[e] contextual control into the hands of research participants» (*op. cit.*: 479). In addition, it is hardly realistic to envisage a request for the signature of a document confirming consent at the time of every observation, even without counting the risk of disrupting ongoing interactions and the work in progress.

These methodological issues go some way to explaining the complex relationship, sometimes involving resistance, between anthropologists and the institutionalization of *procedural ethics*. Anthropologists point to the need for a degree of prudence with respect to formal restrictions, the application of which could in some circumstances be detrimental not only to the quality of research, but also to the people concerned (Hammersley 2009). Tensions generated by different methodological understandings of the use of informed consent and its implications, recall us the increasing awareness of the political dimension of the relationship between anthropologists and the societies they study, which arose in the profession in the 1970s. Since then, a requirement for reflection has been developed (Blondet et al. 2017), calling on researchers to analyse and interpret their presence in the field as part of the construction of knowledge, thus going significantly beyond the simple question of informed consent as practised in the biomedical sciences (Hoeyer et al. 2005). As we will see, awareness of the political dimension of research has led anthropologists to develop *processual ethics*. Such ethics tend to be characterized by dialogue, reciprocity, and the maintenance of trust, which is often the basis for the relationship with research participants<sup>10</sup>. This approach of ethics is shared by other qualitative social sciences (see for example Burton-Jeangros 2017, Ritterbusch 2012). However, *pro-*

<sup>10</sup> As demonstrated by Martina Avanza (2008) through her research on a xenophobic movement, not every relationship in anthropological research is characterized by empathy and mutual trust. Her analysis highlights two points: that, for researchers, putting ethical principles into practice consists in an arbitrage which often involves taking into account the interests of social actors who do not participate in the research (in her case, the individuals who were the targets of xenophobic speeches and actions); and that critical and thoughtful analysis of the investigative relationship with the research participants provides a minimum safeguard ensuring that the issues related to the presence of the researcher in the field are taken into account (on this subject, see Bouillon et al. 2005).

*cessual ethics* cannot now develop independently of the legal context which, going beyond the IRBs themselves, is tending to make the requirements applying to any research initiative more specific and more rigorous. We shall now explore the extension of State intervention in the practice of research through the introduction or revision of three federal laws: the Federal Act on Research involving Human Beings (HRA), the Federal Act on Data Protection (FADP) and the Federal Act on the Promotion of Research and Innovation (RIPA).

### Uncertainty as to the scope of the new HRA

Switzerland offers an interesting example of the movement towards increasing regulation of research through the establishment of standardized ethical protocols, as the strengthening of its legal framework has taken place recently. For many years, protection of individuals participating in research was missing in the laws. At the time of the first law on the funding of universities in 1968, it was the transfer of knowledge to younger generations and collaboration between researchers that were identified in the first article as «good scientific practice» (Assemblée fédérale 1968: 10, transl.). With the creation of a legal basis for the allocation of funds to research institutes in 1983, new principles were included in the concept of «good scientific practices» (art. 2 and 3): respect for freedom of teaching and research; respect for the diversity of opinions and scientific methods; encouragement of the new generation of scientists and maintenance of the quality of research potential; and international scientific cooperation (Assemblée fédérale 1983: 1087-1088). In the same way, the «good scientific practices» set out in the RIPA in 1983 aim first and foremost to prevent the use of federal government subsidies for commercial purposes (art. 7), ensure public access to the results of the research (art. 28) and ensure that research is not without scientific and general value (art. 29).

The political will to change the Swiss Federal Constitution by including an article on «research on human beings» constitutes a notable change of direction in the legal frame-

work for scientific ethics<sup>11</sup>. The constitutional article 118b was approved in a referendum on 7 March 2010 and provided the legal base for the creation of the new HRA. It follows a scandal concerning illegal clinical practices<sup>12</sup> in Switzerland and is motivated by the radical changes in biomedical research based on the great quantity and availability of personal data in digital form – genomic, clinical, and health. Its objective is to «protect the dignity, privacy and health of human beings involved in research» (Art. 1, transl.). As a corollary, the law seeks to create conditions favourable to research, guarantee its quality and ensure its transparency. It should be noted that the law does not apply to any given academic discipline but to the field of health in which research activities are undertaken, to the research questions envisaged and the methods used.

Interpreting the scope of the HRA is an important challenge, given the open definition of the field of health to which it applies. In the consultations held during the development of the HRA, to which the SAA made an active contribution, the Swiss National Science Foundation (SNFS, *FNS* in French) certainly welcomed the proposal to establish a legal framework of this sort, but highlighted a number of weaknesses present in the first drafts of the law. In a press release of 31 May 2006, it stressed in particular the ambiguous definition of the scope «research in the field of health» and pointed to potential adverse consequences: «In addition to medico-biological research, it [the description] could include all empirical research in the social and behavioural sciences. The SNFS considers that the law should instead be limited to cover only those areas where scientific research could have an actual impact on the health of the individuals involved» (FNS 2006: 1, transl.).

In the act eventually adopted, the definition was modified to take account of these reservations. The scope is now defined as follows in the first paragraph of article 2: «This Act applies to research concerning human diseases and concerning the structure and function of the human body, which involves: persons; deceased persons; embryos and fetuses; biological material; health-related personal data» (Assemblée fédérale 2011: 1, transl.). While the definition has become more precise, it nev-

<sup>11</sup> Note that the Swiss legal framework for scientific ethics has also been changed in 2006, after the acceptance by popular vote of a new constitutional article concerning the financial aid to universities. It introduced accreditation and quality assurance processes (Conseil fédéral 2009).

<sup>12</sup> Known as the VanTX affair. For several years, a Swiss research and development company had recruited volunteers, mainly from Estonia, to participate in clinical trials in Basel. The research participants did not receive adequate information, the consent form was not translated into their mother tongue or in a language they understand well enough. Clinical trials were planned on a very short term and participants were sent back home immediately after without medical follow-up. In addition, the activities were carried out without notification to the Estonian authorities, which is illegal according to the Estonian legislation. In the spring of 1999 the scandal broke, drawing attention to the lack of State regulation of clinical trials in Switzerland. Strikingly, the role of this affair in the creation of the HRA was not recognized in discussions among social science researchers around the new HRA (Perrin 2017).

ertheless remains ambiguous in relation to many research projects in the qualitative social sciences<sup>13</sup> which collect personal information – often in an indirect manner – related to health.

An ethicist at the Swiss Federal Office of Public Health (FOPH), responsible for communications on the regulation of research on human beings, whom we contacted, said on this point: «For the social sciences, only those projects which cross-reference health-related data with data including biomarkers (biological or genetic material) such as laboratory test results are within the scope of the law» (interview notes, transl.). According to a member of a cantonal ethics committee, while health-related data may be collected in a range of ethnographic research projects, only those projects which actually aim to produce knowledge in a medical or health field are within the scope of the law. According to a member of another cantonal ethics committee, it is access to medical files as research material that constitutes a determining criterion, even if most decisions are taken on a case-by-case basis. This highlights both the lack of clarity around the practical application of the law in relation to ethnographic projects and the margin of interpretation left to cantonal ethics committees. The extent of the HRA thus remains partially undefined, in spite of attempts at clarification by the FOPH in 2013 and by Swissethics<sup>14</sup> in 2014 and 2015.

Initiatives have been taken at various levels to tackle these uncertainties<sup>15</sup>. In 2015, the Swiss Academy of Medical Sciences (SAMS, *ASSM* in French) published a practical guide, revised and amended to take account of the HRA. The guide, which is recognized by Swissethics as a useful tool, reviews the main issues relating to the HRA and sets out the «good practices» which should be followed. It stresses the importance of avoiding an over-literal interpretation of the legislation: «[...] continual critical questioning of established ethical standards is essential, not only within the scientific community but also by the general public» (ASSM 2015: 18, transl.). The guide recognizes that the definition of the scope of the law

is open to interpretation and that it is being applied on a case-by-case basis. One of the points raised is what constitutes and does not constitute «research», on the model of «quality assurance projects». In cases of doubt, the guide recommends that advice should be sought from cantonal ethics committees<sup>16</sup>.

These uncertainties are creating dissatisfaction among researchers and amendments to the law are already expected in 2019-20. One of the central questions that should be resolved is whether the scope of the HRA should be clarified or whether ethical procedures should be extended to all research projects, whatever the field of study and the discipline. Meanwhile, all those involved, institutions and individuals, are doing their best to interpret the legal framework, depending on their position in the scientific research supply chain, from funders to researchers.

The SNFS is thus leaving it to those who submit research proposals for funding to decide whether their project requires an ethical assessment. It is therefore the researchers who must tick the box to state whether or not their project constitutes «research involving human beings». If applicants do not tick this box, it is not within the SNFS' terms of reference to check that the research complies with the HRA. Researchers must therefore use their own resources – or the support of the institution for which they work – in order to decide whether their projects fall within the HRA, and consequently adjust them with the procedures specified by each cantonal ethics committee.

### Reorganization of cantonal ethics committees and institutional responses

Following the coming into force of the HRA, the cantonal ethics committees, which had often developed within university hospitals, were reorganized in terms of region, size and membership, with a view to optimum rationalization of their

<sup>13</sup> It should be noted that researchers in the quantitative social sciences also have questions about appropriate methods of evaluation for their projects and that projects using mixed methods raise yet another set of questions.

<sup>14</sup> Swissethics is a public interest association (*association d'utilité publique*) founded in 2011. Its purpose is «to ensure coordination between cantonal ethics committees to enable consistent application of HRA and to encourage exchange of information and opinions» (Swissethics 2016, art. 2.1, transl.).

<sup>15</sup> It should be noted that these initiatives are mainly carried out by representatives of the medical sciences, as clearly shown by the model of «general consent» developed by SAMS and Swissethics, which is currently undergoing a second round of consultation (ASSM 2016). Under certain conditions, the HRA allows the establishment of a «general consent» through which participants may accept the use of their data and samples in subsequent research projects.

<sup>16</sup> Since 1<sup>st</sup> January 2016, submission of research projects to cantonal ethics committees should be through the BASEC (Business Administration System for Ethics Committees) internet portal. The submission form provides clarification for the researcher on whether their project requires review by a cantonal ethics committee.

operations. Cantonal and regional committees on the ethics of research involving human beings were put into place with the objective of optimizing available resources and managing applications for assessment, which vary in number between cantons.

Committee members generally have a background in biomedical science or the law. As an example, the Geneva ethics committee, at the time of drafting of this article, has 38 members, of whom only eight are not members of the medical or a paramedical profession<sup>17</sup>. Moreover, although this committee is the first in Switzerland to include a patients' rights advocate, it does not have a single member representing the qualitative social sciences. This significant under-representation shows not only that researchers using qualitative methods do not consider that such ethics committees, which focus first and foremost on biomedical research, are relevant to them; but also that they have a different understanding of ethical questions, as we will discuss below.

In response to the institutionalization of *procedural ethics*, to the demand from funding bodies and scientific journals for ethical guarantees, and to the uncertainty as to the scope of the HRA, some attempts at adjustment have recently been suggested. A number of universities have taken the lead, by introducing their own bodies to regulate ethical issues internally. Although there are wide variations in institutional practices, a general tendency is emerging: to strengthen procedures relating to research ethics, taking account of the HRA legal framework.

The institutions are now taking more assertive positions by means of various strategies, ranging from a requirement for regulation by IRBs to which recourse is compulsory (including for student coursework) to leaving the assessment to research teams (Burton-Jeangros 2017). Some higher education institutions are opting for a non-regulation of this question and offer no general guidance on research ethics. Others encourage reflection on academic integrity, focusing on issues of fraud or plagiarism.

In regard of the formal requirements for research within the HRA, none of these initiatives can substitute for the cantonal ethics committees. They are nevertheless intrinsically linked to the legal requirements and operate where appropriate as a point of articulation between funding bodies – the SNFS or, often, private foundations –, the universities, cantonal ethics committees and researchers. As an illustration of this intermediary role, the institutional ethical review board put in place

by the University of Neuchâtel presents itself as a point of contact between researchers and the cantonal committee. In particular, it offers support for the assessment of ethical issues enabling a decision to be taken on whether (or not) it is necessary to submit an application to the cantonal committee, while taking account of the concerns of the researcher. It also promotes training in research ethics for researchers.

### Alignment with European standards and institutionalization of restrictive norms: the revisions to the FADP and RIPA

While the HRA has brought the issue of research ethics to the forefront of debate within the qualitative social sciences<sup>18</sup> and contributed to its institutionalization, the implications of the total overhaul of the FADP have remained obscure. However, difficulties reported to the EDTT by researchers who are members of the SAA point to obstacles to the conduct of research projects arising not from the HRA but from the FADP. What is this law and what are its implications for anthropologists? The FADP aims to protect individuals and legal entities (companies and associations) from adverse effects – affecting privacy, reputation or creditworthiness, or giving rise to the possibility of surveillance – resulting from the processing of personal data. The concern to protect data in a society marked by increasing opportunities arising from information and communication technologies was reflected as early as 1971, in a first parliamentary motion. This was followed by two parliamentary initiatives, recorded in 1977, calling for the development of a federal law on data protection (Conseil fédéral 1988: 434). The FADP was finally passed in 1992. It aims first and foremost to achieve a balance between the needs of the economy and industry, on the one hand, and the protection of the individual, on the other. However, medical research is a very substantial component of it, because of the specific issues raised by the lifting of medical secrecy for research purposes. Considering that this constitutes a public good, the FADP authorizes the processing of personal medical data for research purposes subject to informed consent (*op. cit.*: 529-530).

Other research activities are also affected, although marginally, by the regulation of data processing. The messages accompanying the original law and its current revision (*op. cit.*, Conseil fédéral 2017) recognize the specific characteristics of research, which is placed in the same category as planning

<sup>17</sup> There are two lawyers (*avocats*), one legal expert (*juriste*), one patients' rights advocate, one minister of religion, one chaplain, one technical and skills transfer associate and one biostatistician.

<sup>18</sup> See for example: Burton-Jeangros (2017), FORS (2017), Berthod et al. (2010), Swiss Sociological Association (2007).

and statistics, because their purposes do not relate directly to their subjects. While the law recognizes that research is in the public interest, it requires that processed data should be anonymized. Research findings can therefore be published, provided that they are anonymized; meaning that it is not possible to identify research participants. However, the FADP creates a special category of data, «sensitive personal data», which are subject to a special legal regime because of increased risk of harm to individuals. Under article 4, paragraph c of the current draft law, this category includes data: «on religious, philosophical, political or trade union opinions or activities»; «on health, private life, or racial or ethnic origin»; «on genetic data»; «biometric data allowing unique identification of a natural person»; «on administrative and criminal proceedings and penalties»; «on social assistance measures» (Assemblée fédérale 2017: 6816-6817, transl.). Aiming to be comprehensive, it subjects the processing of such data to consent which should be explicit, free and informed, thus making it an essential step for research, across all disciplines.

The current extent of digitization of data, or *big data*, together with the open access policies (Leonelli et al. 2017, Wyatt 2017, Coll 2016, Banister 2007) promoted by funding bodies, are central to the current total overhaul of the FADP. They thus feed into discussions around data protection and consent. Although the phenomenon is not yet observable in the Swiss context, research ethics have become the subject of litigation in a number of countries, including the United States, Canada<sup>19</sup> and France (Atlani-Duault et al. 2014). The ease with which research findings circulate outside the research environment, together with the fact that it is often impossible to anonymize them completely<sup>20</sup> for the group of individuals concerned, contribute to the emergence of proceedings attacking researchers for defamation following the publication of research findings (Avanza 2011, Laurens et al. 2010). These proceedings highlight the ways that certain participants with sufficient socio-economic resources can impede the dissemination of research findings.

Our analysis of the RIPA shows that its recent complete overhaul takes account of changes in international standards. Since 2012, the new RIPA has included provision for respect for the principles of «scientific integrity» and «good scientific practices» which had been absent from previous partial revisions: «The research funding institutions ensure that research

which they support conforms to the rules of scientific integrity and good scientific practice» (Assemblée fédérale 2012, art. 12.1, transl.). As part of this, the first paragraph of the article 12 «defines the principle of respect for good practice as a general standard» (Conseil fédéral 2011: 8141, transl.) and contributes to the integration of new scientific standards in Switzerland.

Free access to research data – *open data* – for validation of the reproducibility of results has become an international principle of «good scientific practice» (this is the case, for example, in the European Horizon 2020 research programme). The requirement to submit a Data Management Plan (DMP) for any research proposal submitted to the SNFS since October 2017 thus creates a new administrative burden on researchers. While its aim is to increase the comparability and interoperability of research data, and the validity of scientific findings, this new institutional demand also shines a spotlight on the issues related to data protection. One of the issues is the implications of these new requirements in terms of financial resources and time. As reported by the Canadian researcher Felices-Luna (2016), a change in the place where data were stored, not anticipated at the time of the application for ethical approval, forced her to resubmit a research protocol to the committee, involving a heavy administrative cost. Another issue is the challenge created by anonymization of data for the purpose of data sharing. There is currently no registered procedure in Switzerland and in the absence of this, the precise extent of the FADP in relation to the processing of data from qualitative research remains uncertain. However, as a researcher working on archiving of social science data reported to us, in practice the data are made as secure as possible to prevent any future claims through the courts. One notable consequence of this is to make explicit written consent a compulsory prerequisite for data processing and archiving, including for secondary use of data.

The increase in administrative restrictions linked to data management highlights the tension between *procedural ethics* and *processual ethics*. The requirement for explicit written consent for any research project provides a good example of this. This institutional requirement tends to reduce the question of ethics to a concept of legal protection (Jacob 2007), while anthropologists defend the idea that research ethics goes far beyond the management of consent (Berthod et al. 2010). The revision of the FADP aims to integrate the new European standards introduced by the General Data Protection Regulation (GDPR), which comes into

<sup>19</sup> In 2016, in proceedings against a company, an affiliate professor at the University of Quebec in Montreal was ordered by the superior court to disclose the names of individuals who had participated in the research she had carried out as part of her doctorate in communication. This affair caused the scientific community to mobilise in defence of the confidentiality of data produced in research (Gravel 2016, Kondro 2016).

<sup>20</sup> On the question of the issues around confidentiality and anonymization, see, for example: Lancaster (2017), Saunders et al. (2015), Baez (2002).



force on 25 May 2018. Because of the importance of the issues at stake, we consider it important to reflect on this tension and the different options for responding to it.

### **Between *procedural ethics* and *processual ethics*: tensions in research practices**

This second part of the paper explores the tensions between *procedural ethics* and *processual ethics* in relation to the positioning and practice of anthropological research. The difference between these two understandings of ethics is manifest in the different responses to the scandals that have marked the history of the biomedical sciences, on the one hand, and anthropology, on the other. While the former focused their attention on the rights of individuals to protection and informed consent, the latter have rather positioned ethical concerns as part of a politicization of research and the development of reflective, situated and relational approaches (Ellis 2007, Ferdinand et al. 2007, Hoeyer et al. 2005). In order to understand the specific nature of research ethics as it has developed in anthropology, it is necessary to study the way in which it emerged.

#### **Field relations, power relations?**

Fundamental reflection on the rights and protection of research participants emerged in the 1970s, linked to geopolitical reformulations arising from the processes of decolonization. These reformulations radically changed the traditional research object of anthropology – small scale societies considered as «other» – and so provided the opportunity for critical review of the history of the discipline and the knowledge produced until then. In a general climate of social change, both the conditions in which knowledge was produced and the ways in which such knowledge was used were reconsidered in the light of the complex power relations between colonizers and the colonized, thus leading to questioning at the heart of anthropological reflection on the relationship between knowledge and power (Clifford et al. 1986).

In this context, politicization of the moral responsibility of researchers and the development of epistemological and methodological rather than procedural responses emerged. Reflexivity became an essential constituent of the anthropological approach, to the extent that the analysis of relationships with research participants and with social situations became an integral part of the approach, from access to the field to the publication of results. Seeking to develop a more symmetrical relationship between researchers and participants, dialogical and polyphonic approaches (Crapanzano 1977, Dwyer 1977)

were also developed in order to give more weight and visibility to the voices and visions of people under study. While criticized as representing political reductionism, with the relationships between participants and researcher reduced to a question of writing (Muller 2004, Rabinow 1985), these attempts contributed to the development of participative and collaborative research models (Boser 2007). In such approaches, the researcher's questions are made shared with the participants by providing them with regular reports and discussing the findings, while leaving the researchers free to analyse and interpret (on processes of restitution of results see in particular Olivier de Sardan 2014, Ossipow 2014).

The politicized and relational ethical approach developed by anthropologists has led them to place the question of informed consent in a wider research context. This is justified, in their view, by the fear of reducing this reflective political awareness by focusing the ethical issues on the informed consent procedure, which would become devoid of content, a simple administrative procedure, serving principally to provide legal protection for the institutions and researchers without taking account of the complexity of the multiple ethical issues confronting anthropologists when conducting research in the field. As stressed by Lederman (2006b), these issues are characterized by considering a multiplicity of stakeholders with varying understandings of what is «good» or «fair». Raymond Massé provides a useful summary of the anthropological conception of the relationship between power and ethics:

*The field of ethics is [...] concerned with individual and collective mechanisms for arbitrage and resolution of moral conflicts. However, in every society, these processes of arbitrage reflect existing power relations between the various interest groups which participate in the discussion. Ethics is therefore a space for the comparative analysis of models for the resolution of moral conflicts and economic, political and religious power relations which influence the reproduction (or marginalization) of certain moral values. It recognizes that consent and moral consensus are often forced and that they are consequent on socio-political uses of moral norms.* (Massé 2016, transl.)

Unlike *procedural ethics*, the *processual ethics* promoted by anthropologists thus holds to the idea that neither ethical protocols nor deontological principles provide rules for the ethical and moral questions that arise in the course of research, including fieldwork, data analysis, writing and dissemination of results. In line with the inductive and processual nature of the approach to research, it is the researcher's responsibility to consider them as they arise and resolve them, in particular in dialogue with the participants and the colleagues concerned (Berthod et al. 2010). The will to support *processual ethics* is

reflected in the non-restrictive ethical principles promoted by anthropological associations such as the American Anthropological Association (1971, see Fassin 2008) and the SAA. These principles are based first and foremost on respect for the individuals who are the subject of study, in particular in terms of anonymity and confidentiality. Rather than promote *procedural ethics* or rely on assessment by IRBs, they have tended to rely on the «reputation» of the institutions involved in the research, such as universities and funding institutions, and on the approval of peers and research participants.

### Ethical science, good science?

What are the effects of the epistemological, methodological and political tensions between *procedural ethics* and *processual ethics* on the identity of the discipline and research practices? In recent years, there has been renewed interest in ethics and morality in anthropology, to the point that certain authors speak of an «ethical turn» (Throop 2016, Fassin 2014, Caplan 2003)<sup>21</sup>. While power relations have served as the basis for critical analyses developed in anthropology, they have also reached certain explanatory limitations, partly leading to this ethical turn (Keane 2016). However, these fundamental questions about the place of ethics and morality in anthropology and the posture of the researcher when she or he investigates ethics or morality remain very far from the practical questions and administrative actions to which anthropologists submit when their research proposals are allocated for assessment by an ethics committee.

Contrary to the development of *processual ethics* which characterizes anthropology, the regulation of research ethics instead institutes *procedural ethics*, inspired by the biomedical sciences. In the biomedical world, since the 1990s, research ethics has become institutionalized, particularly because of the importance of the ethical and social issues raised by research on the human genome. While the starting point is a vision of «good» science, disinterested and objective, which can be distinguished from the abuses linked to its social uses (Kerr et al. 1997), the integration of ethical concerns has become central to research activities. Ethics is thus contributing to the establishment of distinctions between «good» and «bad» science, related to the higher or lower ethical standards respectively applied in

practice (Wainwright et al. 2006). This leads to a simultaneous internalization by researchers of ethical concerns and delegation to regulatory authorities, which cause the weight of ethical responsibilities to be laid on external bodies, thus allowing it to be removed from the researchers themselves.

In this context, where adherence to *procedural ethics* is used to distinguish «good» research practice from unethical one, anthropologists find themselves in an uncomfortable position. The round table organised by the EDTT during the 2016 SAA annual conference (see footnote 5) provides an illuminating example of this. Following criticism of the formalism which is guiding the institutionalization of research ethics, two critical issues emerged. The first concerns the perception of the discipline by non-anthropologists, who might consider that the «methodological exceptionalism» defended by anthropologists tends to deny the risks incurred by their research participants.

The second issue concerns obstacles to interdisciplinary dialogue. Anthropologists are tending to adopt a defensive posture and to show that the *processual ethics* which they support reflects higher ethical standards than the *procedural ethics* of the committees. However, rather than encouraging a deeper understanding of the two types of ethics, this posture, by presenting the research practices of anthropologists as being able to do without any form of external regulation, tends rather to increase the dogmatism of the positions on both sides.

One of the challenges currently confronting anthropologists is therefore to legitimize the criticism of *procedural ethics* and the degree of resistance to third party evaluation which results from it, while affirming the ethical nature of their research practices. Indeed, although the focus on arrangements for formal consent applied by cantonal ethics commissions on the biomedical model is considered as problematic, the concern to protect research participants is fully shared by anthropologists. The question is how to develop a common ethics which has the will to protect individuals at its heart, while recognizing that the means of achieving this may diverge. The concept of protection actually arises from a vision of research in which the participants consent to take risks in the name of the advancement of science and in return should be protected by third party agencies – the ethical regulatory authorities –

<sup>21</sup> At international level, we observe a boom of publications about the ethical dilemmas experienced by anthropologists and the solutions they have found. Among these, we note the *Problematorio blog* (<https://problematorio.wordpress.com/blog>); the Field Notes: Ethics series in the journal *Cultural Anthropology* (<https://culanth.org/fieldsights/215-field-notes-ethics>) and the forthcoming publication *Case Studies in Social Science Research Ethics* (<http://methods.sagepub.com/writeethicscase>), the Qualitative Social Research Forum (<http://www.qualitative-research.net/index.php/fqs/browseSearch/identifyTypes/view?identifyType=Debate%3A%20Ethics>), not forgetting the *Ethical Case Studies in Ethnological Research* published by the EDTT and mentioned in footnote 4.



which will check that ethical principles are respected, weighing the benefits of the research against the risks incurred by research participants. This vision considers the research participants as vulnerable people whose interests need to be protected from the enthusiasm of the researchers and defines the research activity as *a priori* dangerous (Felices-Luna 2016).

However, it can be the case that anthropologists study groups of people who have more prestige and power than they do. If, according to this logic, such people must also be protected, there is a risk that they will dictate the results of the research and extinguish all the critical value of an anthropological approach, which aims, above all, to question what is understood as common sense, to take a sideways look at its subject and to create unexpected relationships between data, giving rise to reflection, rather than answering questions (Boden et al. 2009). In addition, it is impossible to know in advance the extent to which the findings of a research study will be capable of harming any given group of stakeholders, as the uses of research sometimes take surprising forms (Bamu et al. 2016, Hoeyer et al. 2005).

The issue here is ultimately about recognition of the legitimacy of the ethnographic approach, once its specific characteristics have been explained. What room for manoeuvre is available to researchers and representatives of the anthropology profession in the face of the institutionalization and bureaucratization of research ethics? What are the options for positioning and action in the face of these developments in the processes of legitimization and control of research? In order to address these questions, we will present and discuss three possible postures which anthropologists could adopt and characterize the risks and issues associated with each of them.

### Moralism, pragmatism and dialogue: postures and alternatives

The first posture, which we describe as moralist, is the most radical. It consists in contesting the authority of ethics committees because the criteria applied by them are not appropriate to ethnographic research and their real effectiveness in protecting research participants is questioned. This would be a refusal to participate in an exercise seen as having undesirable effects on the research itself and in particular in a contractualization of research relationships originally constructed on the basis of a concept of ethnographic engagement. The concrete objective of such a posture would doubtless be to convince as many people as possible of the specific and different nature of ethnographic approaches and ultimately to obtain differentiated treatment in relation to ethics. However, the main risk related

to such positioning is that it would undermine the scientific legitimacy of research practices, by giving the impression that the discipline rejects the validity of ethical questions themselves, or less radically, that it refuses to delegate the validation of research ethics to an external body. The problem is that while the concept of anthropological engagement is meaningful to anthropologists and their closest colleagues, it is less clear that it is convincing to a wider public, particularly as this posture implies that the anthropologist is the only person who can judge the ethics of his or her own engagement.

A second posture would consist in working within the system, without engaging with it more than necessary. It takes its inspiration from ethnographic pragmatism, which has long demonstrated the limits of the ability of institutions and rules to restrict individual practices, as researchers have made use of room for manoeuvre, inventing ways round and strategies to avoid obstacles. The concept of the undesirable effects of the institutional arrangements is still present in this option but the response is different. Situated between challenge and pragmatic acceptance, it involves submitting to the new procedures and playing the institutional game, without necessarily subscribing to the principles underlying them. The challenge here is to maintain the specific characteristics and freedoms of the discipline of anthropology while adapting to the new constraints of *procedural ethics*. We see two risks in such a posture. The first would be an implicit reduction of the question of ethics to this form of «procedural detour». Would there not be a risk that anthropologists would accept that the question of ethics came down in the end to this superficial participation and treatment? Secondly, any administrative and linguistic framework has a performative dimension. Bending to ethical standards developed for other methodological and epistemological approaches carries the risk of radically changing ethnographic research, both in its objects – through the avoidance of sensitive issues – and its methods, for example by encouraging formal interviews rather than participant observation. While this option is in fact now widely adopted in response to increasing formal ethical requirements, we consider that the associated risks are undesirable.

Finally, the third posture we wish to set out here is that of participation in dialogue around research ethics and engagement in its institutionalization. It is based on the hope that ethics committees will become more open to *processual ethics* and to progress in the quality of the treatment of ethical questions in the cases specific to ethnographic research. Such a posture has been promoted by a range of researchers (see, for example, Lederman 2006c). It involves acceptance of the idea that action is required on the regulation and governance of research ethics, whether for societal or for more fundamental ethical reasons. This position brings a critical but open mind to bear on the current operation

of the institutions responsible for research ethics, and aims to engage in the debate in order to improve the institutional treatment of research ethics. The main risk of participation lies in the possibility of more rigid positions and aggravation of mutual misunderstandings. The risk of failed engagement would be to lose the opportunity for institutional improvement, while having contributed to undermining the basis for a more comprehensive resistance to the process of bureaucratization of ethics.

The possible ways of achieving such participation remain to be discussed in more detail. We can see two main alternatives here. It would be possible to promote the inclusion of anthropologists and other social scientists who use qualitative research methods within existing ethics committees. This would involve accepting their operating methods and activating a dialogue between representatives of *procedural ethics* and *processual ethics*. This choice would seek to reform the institutions from within by increasing their specific skills relating to qualitative social sciences, which could be mobilized when required, while maintaining the cross-cutting and generalist nature of the committees.

The second alternative would be to create committees specific to disciplines or groups of disciplines, such as an ethics committee for the social sciences. This implies acceptance that a «committee» is a suitable instrument for the needs of the researcher in terms of research ethics and of the formality that it involves, even if it is possible to enlarge its objectives and role, so that it is more focused on the needs of researchers. An argument in favour of the creation of discipline-specific committees is the competence of the experts to assess research proposals in terms of their methodological, epistemological and ethical specificities. Rather than see projects promoting *processual ethics* assessed in the light of *procedural ethics* criteria, this would mean developing forms of assessment adapted to the specific features of our discipline. It might also be the case that a committee composed of experts in the discipline would be in a better position to identify attempts to evade or get around ethical criteria within a project.

One of the fundamental questions that would be posed by the creation of a committee specific to a disciplinary field is that of the cross-cutting nature of ethical criteria. Nevertheless, the constitution of committees specific to qualitative social sciences would have the advantage of developing new formal approaches, of adjusting the assessment criteria, and of including greater complexity. In other words, it would encourage the articulation and integration of *procedural* and *processual* ethics. Such committees might be organized within universities or at the level of professional associations, such as the SAA. In order to avoid the multiplication of isolated initiatives, it seems important not to lose sight of the resulting communication and coordination needs. It would be essential to open up a discussion on

the establishment of such committees and their ways of working, not only within the anthropology community but more widely among researchers in the qualitative social sciences.

Finally, because of the importance of the ethical questions faced by students and researchers in the conduct of their fieldwork, we consider it crucial to promote dialogue around research ethics by creating a range of spaces for it, and to support interdisciplinary education in research ethics, which remains rare in universities.

## Conclusion

As background to the debate on regulation and control of research ethics, it is useful to remember a fundamental difference between two approaches to the question of ethics. The first focuses on participants and their protection. It is the basis for the development of ethics committees and the principle of informed consent. As we have seen, its source lies in the major scandals which tarnished the history of medical research in the 20th century. On the contrary, the second approach draws attention to the social and political implications of research activities in a much broader way. In response to scandals related to the uses of social sciences in (post)colonial and hegemonic State projects, anthropology and the qualitative social sciences recognize the political and situated dimension of scientific knowledge and favour the second approach. These two ethical approaches are reflected in two different definitions of the problems that could result from participation (or not) in research. To put it in simple terms, the first approach frames the question in terms of individuals and direct impacts, particularly in relation to the physical or psychological safety of the individual. The second integrates the phenomena of collective domination and social critique and asks itself questions about the relationship between research practices and social (re)production.

These two ethical approaches may complement each other's. Nevertheless, emphasizing on one or the other leads to profoundly different ethical positioning. When this difference between systems of representation of ethics is not defined, it undermines the debate and leads to mutual misunderstanding. The fundamental point is that formal procedures for regulation of research ethics tend to leave no space for ethical approaches related to social critique. In recalling the critical and reflective dimension of ethics, we see a fundamental role for the social sciences to play in the regulation of research ethics. Rather than focusing on whether or not tools such as ethics committees or informed consent forms are suitable for ethnographic methods, there is a need for reflection on new, complementary, tools, which will question the societal consequences of research.

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