9. Research ethics for human rights researchers

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INTRODUCTION

The fact that human rights research is conducted in pursuit of a good cause in no way exempts practitioners from ethical scrutiny and accountability. To the contrary, it is often the case that the capacity to do good is matched by a corresponding risk of inadvertently inflicting harm or otherwise violating the integrity of research participants – and hence the need for ethical awareness and scrutiny is all the greater.

Research in the area of human rights, like human rights practice, invariably concerns issues that in one way or another are sensitive and charged. It may involve population groups whose lives are in jeopardy or who are exposed to imminent risks of abuse. It may involve recently traumatized individuals and communities, or it may touch upon issues that are deeply contentious and politically divisive.

That said, the academic contexts and methodologies of human rights research vary widely, and so do the ethical implications. Doctrinal legal analysis is less likely to pose immediate risks of harm than field research involving living human beings, yet both may be ethically charged in their long-term effects. In some cases the line is blurred between academic analysis and fact finding about particular instances of human rights abuse, thus raising the ethical stakes even further. Research methodologies such as critical policy analysis or archive-based historical research may not have direct consequences for identifiable individuals but may be sensitive and controversial in terms of their social and political implications.

Research ethics is a branch of professional ethics that addresses scientific conduct.[1] In addition to commonly applicable ethical standards, it is premised on values of scientific integrity, honesty and contributing to

[1] For a general overview of what research ethics is about, see, e.g. David Resnik, 'What is Ethics in Research and Why is it Important?' (2011) 8 National Institution of Environmental Health Sciences <http://www.niehs.nih.gov/research/resources/bioethics/whatis/> accessed 20 May 2016. See also A. Shamoo and D. Resnik, *Responsible Conduct of Research* (2nd edn, OUP 2009).

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the public good through the pursuit of knowledge (which in the present context may imply providing a knowledge base for the advancement of human rights).

There are a multitude of sources of ethical guidance available to researchers. Some have been adopted by professional organizations to guide scientific conduct within particular academic disciplines, some have been elaborated by funding agencies and some apply specifically to researchers undertaking their work in a particular institutional context. Some ethics guidelines are purely instructive in nature, whereas others are obligatory in a given context. The present chapter will make reference to some such ethics resources of relevance to research in the area of human rights.[2]

The main focus of the chapter, however, is on the *issues* in need of attention. The author presents an analytical framework which distinguishes between five primary levels of ethical consideration. This provides a basis for scholars to identify the ethical implications of their proposed or on-going research and take appropriate measures in response to the relevant ethical concerns. In a wider sense, the aim of the chapter is to contribute to ethical awareness-raising within the community of human rights researchers and facilitate discussion about ethical dilemmas and challenges in an open and proactive fashion.

Ideally, the focus on ethics should be viewed as an integral aspect of research methodology. While it cannot be excluded that ethical considerations from time to time will run counter to a given methodological approach, and may be experienced as inhibiting scientific expediency, the general presumption of the chapter is that ethics and good science usually go hand in hand. A high level of ethical compliance is generally conducive to positive research outcomes, and it is incumbent upon researchers to pursue synergies, or at least consistency, in this regard.

This is particularly relevant in a normatively defined context such as human rights research. A natural source of guidance for research in this area can be found in the international human rights framework itself.

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[2] Ethics codes and reference documents that have inspired the present discussion include: Council for International Organizations of Medical Science (CIOMS), *International Ethical Guidelines for Biomedical Research Involving Human Subjects* (2002); American Anthropologist Association, 'Statement on Ethics' <http://ethics.americananthro.org/category/statement/> accessed 20 May 2016; National Committees for Research Ethics in Norway, *Guidelines for Research Ethics in the Social Sciences, Law and the Humanities* (2006); and Nuffield Council on Bioethics, *The Ethics of Research Related to Healthcare in Developing Countries* (2002).

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While this first and foremost obligates states, it also entails important 'horizontal obligations' for social actors at different levels, including scientists and other professionals. A further aim of this chapter will be to elaborate specific implications of the 'ethos of human rights' and demonstrate how this resonates with core principles of research ethics. This is a dimension of research ethics that so far has not been well illuminated in the literature.

A final question addressed in this chapter has to do with enforcement and accountability. In keeping with the overall aim to contribute to ethical awareness-raising and discussion within the community of human rights researchers, the focus in this regard will be on a notion of situated, 'soft' accountability rather than on the quasi-judicial enforcement of a narrow set of rigidly defined norms.

ANALYTICAL FRAMEWORK: WHAT IS ETHICS ABOUT?

An important first step towards enhancing ethical standards of conduct within a profession, including among scientists, consists in raising awareness about the issues in need of attention and supplying practitioners with the tools to identify and analyse the possible ethical implications of their proposed or on-going practice. This can be framed in terms of an inquiry into how we conceptualize the realm of ethics. What types of issues are perceived as ethically significant, and is there a shared perception of this not only among practitioners/scientists but also with the communities within which professional practice and research is carried out? Experience shows that it is often more fruitful, especially when working in a cross-cultural context, to seek to develop a common conceptual language and typology of ethical issues than to immediately seek to articulate binding norms.

The pertinent standards of professional conduct can to a large extent, if not exhaustively, be articulated with reference to a limited number of basic normative considerations and commitments.[3] Specifically, it is proposed

[3] Various basic approaches have been advanced in this regard. Bernard Gert, among others, has developed a rule-based approach to medical ethics whereas Tom Beauchamp and James Childress are associated with a principle-based approach. See, respectively, B. Gert, *Morality: A New Justification of the Moral Rules* (OUP 1988); B. Gert, C.M. Cluver and K.D. Clouser, *Bioethics: A Return to Fundamentals* (OUP 1997); and T. L. Beauchamp and J. F. Childress, *Principles of Biomedical Ethics* (6th edn, OUP 2008). The present author's own approach as presented in the following is partially inspired by both schools of thought.

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that there are five main categories of ethical issues that together delineate the field of professional ethics.[4] These are:

(1) *no-harm issues* (about how one's actions and decisions affect others, *what* one does to others – directly or indirectly, physically, materially or psychologically, immediately or in the longer term, by commission or by omission, etc.);
(2) communication issues/issues concerning *recognition* and *respect* (relate to the quality of our interaction, *how* one relates to others, recognition of the competence and autonomy of participants in research, negotiating expectations of reciprocity);
(3) issues having to do with *beneficence* and *justice* (about doing good for others, promoting a greater good, maximizing available scarce resources, ensuring a fair distribution of burdens and benefits, preventing and redressing wrongs, addressing needs);
(4) issues related to *collaboration* and possible *conflicts of interest* (about correct conduct and fairness in the negotiation of vested interests); and
(5) issues of compliance with *scientific and professional standards* and institutional policies.

In what follows, the underlying rationale and core ethical commitments at each level of consideration will be elaborated with particular attention to their application to scientific conduct. At each level, the author will

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[4] The considerations presented in the following are to a large extent based on the author's direct experience of working with ethical problems and challenges in the fields of overseas medical research, social anthropology, international development cooperation, and international human rights field operations. A particular source of inspiration for the author was a study conducted in the mid-1990s on behalf of the Danish Council for Development Research on ethical challenges of donor-sponsored research in developing countries. This involved extensive field work in research environments in East Africa. Findings of the study were presented in the project report *Globally Speaking: Report on the Ethics of Research in Developing Countries* (Copenhagen 1998) and in numerous subsequent publications, including G. Ulrich, 'Optimum Ethical Standards', in 'Proceedings Seminar on Health Research Ethics in Africa' (January 2001) 78 (Supp. 1) Acta Tropica 1; G. Ulrich 'Charges and Counter-charges of Ethical Imperialism: Towards a Situated Approach to Development Ethics' in Ph. Q. van Ufford and A.K. Giri (eds), *A Moral Critique of Development: In Search of Global Responsibilities* (EIDOS, Routledge 2003); and G. Ulrich, 'Elucidating Ethics in Practice – Focus on Accountability' in P.W. Geissler and S. Molyneux (eds), *Evidence, Ethos and Experiment: The Anthropology and History of Medical Research in Africa* (Berghahn Books 2011).

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attempt a provisional mapping of the ethical dilemmas and challenges that may arise in connection with human rights research. Where relevant, linkages will be made with the implicit ethos of human rights and reference will be made in an illustrative fashion to applicable ethics codes and guidelines.

It should be noted that many characteristic ethical dilemmas present themselves at the intersection between two or more levels of consideration, typically in the form of a tension or conflict between competing ethical commitments. Paternalism, for example, denotes a prioritization of one's commitment to doing good for others over the obligation to respect their capacity for self-determination. Utilitarian reasoning, which typically prioritizes the third parameter indicated above, raises questions about the degree to which particular risks of harm are justified by the prospect of a greater good. Cross-cutting issues of this nature will be thematized in an ongoing fashion along the way.

NO-HARM ISSUES

The injunction not to expose individuals or groups affected by one's professional engagements to harm is widely recognized as a foundational principle of professional ethics – also known as the principle of *non-maleficence*. In the context of scientific practice this implies that scientists have a primary responsibility towards research participants irrespective of any greater good that is expected to result from the research.

The principle of *non-maleficence* has been regarded as a guiding principle of medical ethics since antiquity.[5] In a contemporary context, it features centrally in virtually every code of ethics.[6] This echoes a legacy

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[5] Non-*maleficence* is one of four primary ethical principles recognized in the seminal textbook by Beauchamp and Childress (n 3). Within the medical profession, the maxim *primum non nocere* is commonly associated with the Hippocratic Oath. It does not in fact appear explicitly in this ancient text, but has throughout the ages served as a cornerstone of medical ethics. See C.M. Smith, 'Origin and Uses of Primum Non Nocere – Above All, Do No Harm!' (2005) 45(4) J Clin Pharmacol 371ff. For a more narrative account of the complexities and personal challenges involved in honouring the no-harm principle, see Henry Marsh, *Do No Harm: Stories of Life, Death and Brain Surgery* (Weidenfeld & Nicolson 2014).

[6] It thus also applies to the human rights profession and features prominently in the *Statement of Ethical Commitments of Human Rights Professionals* that the present author has taken part in drafting; see G. Ulrich, 'The Statement of Ethical Commitments of Human Rights Professionals: A Commentary' in M. O'Flaherty

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of scandal whereby vulnerable human beings – typically members of discriminated groups – have been callously exposed to abuse in the name of science. The experimentations conducted by Mengele in the concentration camps during World War II and the infamous Tuskegee syphilis experiments conducted in the United States from 1932 to 1972 are two of the most important recent examples.[7] The former led to an express reference to research ethics being included in the ICCPR article 7,[8] and the latter to the establishment of an elaborate system of institutional review boards in the US and around the world.

Analytically, the no-harm principle concerns what one does *to* others, how one's actions affect the well-being of others. This is largely a matter that is within one's own control – at least in the sense that any manifest risk or incident of harm should lead to revising or terminating the given activity. In other words, it is a principle that is largely commensurable with the agency of the practitioner, and hence the injunction not to do harm (in contrast to many other ethical principles) has an absolute character. To operationalize the principle, two important points need to be considered: first, *how to qualify harm* and, secondly, *what types of obligations* the no-harm principle entails.

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and G. Ulrich (eds), *The Professional Identity of the Human Rights Field Officer* (Ashgate 2010). The ethics code of the OHCHR §11 similarly states that '[OHCHR staff shall]: Refrain from endangering, by way of their words or action during or after their service with the OHCHR, the safety and privacy of the people with whom they come into contact and their own safety . . .;' see OHCHR, Code of Conduct for OHCHR staff, Directive No. 2 (1999). Reproduced in 'Norms Applicable to UN Human Rights Officers and Other Staff', *Training Manual on Human Rights Monitoring*, (OHCHR, 2001), pp. 449–464. For an insightful discussion of the application of the no-harm principle to the area of humanitarian assistance and peace building, see M.B. Anderson, *Do No Harm: Supporting Local Capacities for Peace Through Aid* (Local Capacities for Peace Project, Collaborative for Development Action 1996).

[7] See, e.g. G.L. Posner and J. Ware, *Mengele: The Complete Story* (McGraw-Hill 1986); and S.M. Reverby, *Examining Tuskegee: The Infamous Syphilis Study and its Legacy* (University of North Carolina Press 2009). See also A.R. Jonson, *A Short History of Medical Ethics* (OUP 2000).

[8] International Covenant on Civil and Political Rights (ICCPR), G.A. res. 2200A (XXI), 21 U.N. GAOR Supp. (No. 16) at 52, U.N. Doc. A/6316 (1966), 999 U.N.T.S. 171, entered into force 23 March 1976. By stipulating that 'no one shall be subjected without his free consent to medical or scientific experimentation', ICCPR article 7 *prima facie* accentuates another foundational ethical principle, namely, that of autonomy. However, the fact that this is directly linked with a prohibition against torture and other cruel, inhuman or degrading treatment or punishment makes it clear that informed consent is intended and understood as a means of (self-)protection against harm.

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In terms of qualifying the concept of harm, it is relevant to distinguish between:

- physical, mental and material harm;
- direct and indirect harm;
- immediate harm and harm that only becomes manifest in the long term (with delayed effect);
- harm by commission and harm by omission;
- intentional and unintentional harm.

All dimensions of the concept are relevant, which is to say that researchers need to be concerned not only about immediate and direct effects of their actions, but also about harm perpetrated by others as an indirect, sometimes long-term, consequence of research. It is rare that serious harm is inflicted deliberately or even knowingly by scientists. When it occurs, it is (almost always) an unintended consequence of activities that are undertaken with good intentions. The essential ethical requirement, therefore, is to exercise foresight and diligence in ascertaining the possible adverse consequences of one's proposed and on-going research.

The three main obligations incumbent upon researchers are to *anticipate*, *monitor* and *react to* risks of harm. In the clinical testing of pharmaceuticals, a very rigorous attention to risks of harm is built into the progression of phase I, II and III trials, which in essence requires researchers to test and monitor toxicity before beginning to test efficacy. Being less invasive, other areas of science are also less exacting in terms of ethical vigilance, but for research involving human subjects it is as a general rule reasonable to require project descriptions and research protocols to include:

- an explicit and comprehensive detailing of the risks of harm that have been identified as possible outcomes of the proposed research;
- a statement on how such risks will be monitored and managed; and
- a statement on what remedial measures will be taken in case things go wrong (e.g. termination of research, counselling, protection measures, insurance).

In the case of research involving more than a trivial risk of harm or other identifiable inconveniences to research participants, it may also be appropriate to include:

- a statement to the effect that the given risks and inconveniences are proportionate to the expected benefits deriving from the research and therefore justifiable on balance;

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- an account of why the envisioned research outcomes cannot be achieved without the given risks and inconveniences (i.e. an explanation of why the risk factor is necessary); and
- an assurance of an equitable distribution of burdens and benefits, such that the individuals or communities who are exposed to risk and sustain inconvenience also have a realistic prospect of sharing in the anticipated benefits of the research.

Professional ethics recognizes a number of additional requirements and principles which, while motivated by a rationale of their own, are related to the no-harm principle. The principle of *confidentiality* in effect marks a requirement to protect clients and individuals in one's care from the physical, mental or material harm that might derive from the disclosure of sensitive personal information. The requirement to obtain *voluntary and informed consent* (which will be further discussed below), similarly, is widely conceived as a means to empower research participants to protect themselves against harm. Some ethics codes, moreover, include an elaborate set of provisions related to decision-making on behalf of minors, the mentally disabled and other persons who are not fully competent to safeguard their own interests.[9] This too can be understood as a direct extension of the no-harm principle.

Application in Relation to Human Rights Research

The next step of our analysis consists in undertaking a provisional survey of ways in which research in the area of human rights, despite good intentions, may entail risks of inflicting harm. Given the diversity of the research area, this will be far from exhaustive.

Risks of indirect harm

In situations of conflict, social tension or repressive government, there is an immediate risk of exposing research participants to harm perpetrated by others. This can notably happen by sensitive and personalized data getting into the wrong hands. In some cases the mere association with foreign researchers may be a cause of suspicion and possible retaliatory action, as the human rights agenda may be regarded as a treat to local privileges and power structures or to particular groups of local actors. In such situations, researchers carry a heightened responsibility to protect informants and

[9] The CIOMS Guidelines (n 2) are an important case in point; cf. guidelines 9–10 and 13–15.

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ensure confidentiality, undertake data collection in a discrete and protective manner, anonymize and carefully guard research data and interview recordings, etc. Considerations of this nature are particularly relevant in connection with applied research (e.g. post-conflict fact finding or research with direct implications for resource allocation) and research undertaken in contexts of on-going human rights abuse, repression and extreme disparities of wealth and social access.

Risks of direct harm

Human rights research is rarely physically invasive and does not involve 'experimentation' in the sense foreseen in ICCPR article 7. It may however be associated with direct mental harm. Some forms of inquiry may, for example, rekindle traumatic experiences and trigger angst and dysphoria, or they may place research participants in inherently embarrassing and compromising situations leading to severe stress, social exposure, or both.[10] It is often ambiguous whether researchers should be able to anticipate adverse consequences of this nature, but the matter should be given careful consideration in the design of research projects and planning of how interviews and other forms of data gathering are to be conducted. In case of severe dysphoric reactions, it is incumbent on the researcher to immediately terminate or revise the given data collection procedures and seek qualified assistance (with adequate local knowledge) to address the underlying issues. In practice, it is often beyond the capacity of researchers – in particular individual researchers working in meagerly funded academic contexts – to effectively respond to complex social and psychological reactions on the part of research participants. It is for this reason all the more important to pay close attention to risks of mental harm in advance of a given research initiative.

Delayed effect

The issue of adverse consequences of research is not only a concern in the immediate interaction with research participants. There may also be long-term harmful consequences as a result of the manner in which individuals and populations implicated by the research are subsequently

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[10] Stanley Milgram's (in)famous experiments on obedience to authority figures in the early 1960s have been widely criticized for placing research participants in a profoundly compromising situation and were on this account influential in drawing attention to the issue of mental harm in the context of research ethics. For a detailed account of the legacy of these experiments, see G. Perry, *Behind the Shock Machine: The Untold Story of the Notorious Milgram Psychology Experiments* (The New Press 2013).

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portrayed, as this may be perceived to be humiliating and offensive and may have a lasting impact. Questions related to the ethics of representation overlap in many regards with the ethical considerations related to *communicative interaction*, as shall be further examined below, but may also be thematized as a question of mental harm, at times bordering on outright defamation.[11]

The publication of research findings may also be linked with long-term physical or material harm in cases where the findings are intrinsically unfavourable to particular parties in a given social situation, perhaps an on-going conflict or a situation involving competing claims to scarce resources. This is of particular relevance in connection with applied research and studies that have immediate policy implications. The possible adverse outcomes for certain parties in divisive situations need not imply that the research itself was biased, but simply that the results cannot be regarded as neutral.

Harm by omission

Issues of *harm by omission* typically involve a failure to intervene in situations where researchers encounter severe deprivation or witness blatantly harmful or hazardous practices. Health professionals recognize an obligation to take action when confronted with medical malpractice and acute health crises. Human rights professionals, by analogy, may be expected to react when encountering evidence of imminent or grave and persistent human rights abuse. This may, in exceptional cases, entail taking direct personal action, but more frequently the appropriate ethical response will consist in directing the attention of competent authorities to the given concerns.

In practice, the notion of harm by omission is often associated with ambiguity. To shed light on the nature of the ethical obligations to which it gives rise, it is relevant to distinguish between situations that involve a categorical obligation to take action, which by omission would constitute

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[11] Problems related to the ethics of representation have been an important point of concern within the discipline of social anthropology at least since Colin Turnbull's seminal publication of a monograph (*The Mountain People* (Simon & Schuster 1972)) on an indigenous population that he found inherently unlikable. James Clifford and George Marcus's *Writing Culture: The Poetics and Politics of Ethnography* (University of California Press 1986), which draws inspiration from Edward Said's *Orientalism* (Vintage Books 1979), exposes the constructions and power dynamics at play in ostensibly objective and neutral scientific representations. Issues related to the ethics of representation are also, from a different point of view, central to journalistic ethics and media ethics.

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a breach of ethics, and situations that merely involve a perceived responsibility to do good, which one may feel strongly motivated to honour but which conceptually has more of an optional character. One's sense of obligation in the latter scenario may be reinforced by the persistence of local expectations, which often relate to exigencies that fall outside the scope of one's professional engagement and which in a cumulative sense may vastly exceed one's capacity to address. Medical scientists conducting research in deprived communities, for example, are continuously confronted by requests for medical attention that is unrelated to the subject of their research. They may feel a profound sense of personal and professional obligation to respond to such requests, to the best of their ability, but the failure to do so, and indeed the need to draw limits, can hardly be construed as a matter of inflicting harm. In human rights research, similarly, the witnessing of deprivation, oppression and continuous low-level or indeed serious abuse may spur the researcher to campaign for change in all manners possible, but outside a narrow range of situations in which researchers in virtue of their professional status and privileged access to sensitive information are in a position to affect immediate change, the failure to remedy or prevent abuse cannot be construed as harm by omission. Reference to the notion of harm by omission, therefore, should be used sparingly.

Exposing human rights violators to harm?

The possibility of witnessing human rights violations in conjunction with research also gives rise to uncertainty regarding *to whom* the researcher's ethical obligations pertain. This is especially pressing in cases where research from the outset is intended to address unlawful activities and/or involve the participation of identified human rights violators and actors who may be complicit in human rights violations, e.g. by propagating extremist views. Such research may obviously be justified by an overarching interest in understanding the perceptions, motivations, and modes of operation of perpetrators, but publishing research findings and disclosing the identity of informants may seriously expose individuals with whom one has interacted in good faith to harm. Not to do so, conversely, may be construed as a matter of tacitly endorsing human rights violations or failing to prevent future transgressions and thereby contributing to harm by omission. The resolution of this dilemma will typically depend on the severity of the issues at stake and the ability or lack of ability of the researcher(s) to meaningfully contribute to a cessation of the identified abuses. The matter, in any case, remains complicated and requires careful ethical scrutiny in a suitable public or semi-public forum.

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COMMUNICATION ISSUES

The inquiry into ethical perceptions in everyday life (the 'phenomenology of ethics') shows that ethics is commonly perceived not only as a matter of *what we do to and for one another*; it is also, importantly, about the manner of *how we interact*. This is reflected in expectations of being recognized and treated with respect and, conversely, in the hostile reaction that people everywhere display when feeling slighted, misled, humiliated, perhaps even used. For the present purposes this class of ethical issues may be grouped under the heading 'communication issues', as it involves expectations of reciprocity, openness, honesty and transparency that are implicit in our communicative interaction.

In comparison with the injunction against inflicting harm, this level of ethical consideration does not feature prominently in formal ethics codes and review procedures.[12] This may be because the underlying issues are assumed to be 'soft' in nature, i.e. indeterminate and not easily subject to regulation. They are, however, perceived as highly relevant by people on the ground and are particularly sensitive and charged in situations characterized by disparities of knowledge, access and power – which often apply in relation to professional conduct. Issues of recognition and respect also demand special attention in cross-cultural settings, where they from the outset are tenuous and fraught with ambiguity.

The present author's examination of ethical practices in donor-sponsored research in developing countries revealed a persistent and widespread perception that researchers come to 'the field' to collect data for reasons that are not properly explained, i.e. neither intelligible nor immediately relevant from a local perspective. The researchers then simply disappear, attending to their own objectives and interests and leaving the host community with a feeling of having been taken advantage of. Despite promises to come back to the participants with a report on research outcomes, this rarely happens.[13] While it cannot be assumed that such misgivings are indicative of research practices in other contexts, they do underscore the ethical importance of communicative interaction with research participants.

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[12] It does, however, feature as a central aspect of two out of four core ethical principles in the Nuffield Council on Bioethics' report (n 2) pp. 47ff.

[13] Frustrations related to substandard communication are not always openly articulated but are rather expressed in the form of indirect misgivings and rumours attributing illicit motives to the researchers. See, e.g. P.W. Geissler and R. Pool, 'Popular Concerns about Medical Research Projects in sub-Saharan Africa – A Critical Voice in Debates about Medical Research Ethics' (July 2006) 11 in Tropical Medicine and International Health 975ff.

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The primary expression of this dimension of ethics in formal ethics codes is found in the principle of *voluntary informed consent*. Other well-established norms that are relevant in the present context are *anti-harassment* norms and norms related to the protection of *confidentiality*. Both are commonly interpreted as means of preventing harm but also fundamentally concern respectful interaction and the fostering of trust.

Beyond the formally defined standards, there is a range of underlying and less precisely defined commitments that are essential to a genuinely ethical approach to research. These include:

- treating research participants and host communities with respect;
- being open and transparent about research aims, methods and implications of participating in research;
- respecting the right of research participants to freely determine the nature and extent of their involvement;
- displaying sensitivity to the life situation of research participants, including possible vulnerabilities and experience of abuse;
- treating sensitive information with discretion;
- displaying respect for the values and life choices of interlocutors;
- displaying sensitivity to how individuals and groups contributing to or affected by research are portrayed in the presentation of results; and
- a reasonable degree of follow-up and feedback on research outcomes to the involved participants.

Application in Relation to Human Rights Research

Projecting an ethos of human rights

The ethics of communicative interaction resonate strongly with core human rights principles such as *participation*, *non-discrimination*, *social inclusion* and *respect for the dignity of the human person*. The commitments listed above are therefore immediately relevant in the context of human rights research. It is a central premise of the present publication that human rights research, irrespective of disciplinary context and choice of methodologies, must be committed to a high standard of openness and accountability and should be explicit about the value commitments, baselines and judgments that inform and guide the research. This serves as a means of exposing oneself to external scrutiny and as an incentive to being reflexive about impacts of the research.

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Displaying sensitivity

When working with traumatized, vulnerable and exposed individuals or groups, there is a particular need for sensitivity in the manner in which research participants are engaged. Researchers may in some situations find themselves torn between urgently documenting and drawing attention to human rights violations that otherwise remain ignored and treating human suffering with sensitivity and discretion, which may require a less invasive and assertive approach. Such dilemmas should as a general rule be resolved in a manner that prioritizes respect for the dignity of individual research participants. It is by the same token ethically incumbent on researchers to beware of reinforcing stereotypes and portraying identifiable individuals or groups in a derogatory or humiliating manner. This applies both while conducting research and in the presentation of findings.[14] When working in conflict and post-conflict situations and among divided populations, there is an onus on researchers to avoid contributing to a further escalation of hostility by projecting preferences for one party in the given conflict at the expense of others.

Broaching value differences

A characteristic dilemma has to do with how to react to non-human rights-compliant values and practices. The notion of respect for human dignity implies an obligation, implicit in our everyday communicative interaction, to recognize the competence of the Other to form and assert independent value judgments, also when such values conflict with one's own. This, however, does not imply an obligation to remain silent. When confronted with extreme views or patterns of abuse, passive acceptance and inactivity can be construed as a moral failure. The ethical imperative in such situations may be to speak out or take remedial action in other ways.

It is a common experience, conversely, that the values and agendas projected by human rights research are openly or implicitly contested in the local context by certain interlocutors. This may be due to an opposition to the concept and practice of human rights as such. Or it may be due to feelings of mistrust and threats associated with the practical outcomes of research, as is particularly a concern in relation to consultancies, evaluation and monitoring assignments, research involving an explicit advocacy component, and other forms of applied human rights research.

In all such cases, the essential challenge for the researcher lies in broaching differences in a candid but respectful manner and in striking a balance between being transparent about one's own value commitments and giving

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[14] This overlaps with the question of mental harm; cf. n 11.

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space for the articulation of conflicting views, thereby setting the contestation of norms and objectives on a constructive track. This is a challenge with far-reaching practical implications, as human rights practice at every level involves a contestation of norms which reflexive interaction in the research setting may help to illuminate.[15]

Informed consent

Since the Nuremberg Code of 1947, the principle of *voluntary informed consent* has been attributed an absolutely central role in medical research ethics. Increasingly, it is recognized as a core standard in other branches of professional ethics. It *prima facie* reflects a commitment to respect the autonomy and capacity for self-determination of prospective research participants. Upon examination, it is actually a complex principle. *Voluntary informed consent* comprises a right to be properly informed about research methods and aims; a right to freely determine the scope and nature of one's involvement; and, in a wider sense, a right to protect oneself against externally inflicted harm or risks of harm (as discussed above). In practice, these objectives are not always well served by formal consent procedures. Subsequent surveys often show that the information provided in conjunction with the consent procedure was not fully intelligible to research participants and that many elements of direct or indirect coercion come into play in decisions about participation.[16] Formal consent procedures are therefore at best only partially effective in empowering research participants to protect themselves against excessive risks of harm. Being structurally modelled on a legalistic, contractual relation, they are not necessarily conducive to continued reciprocal and respectful interaction. The upshot of such considerations, in the present author's view, is not that informed consent should be abandoned as a core standard of research ethics. Rather, ethically responsible researchers need to keep sight not only of formal requirements but also of the underlying rationale of the principle and of the wider range of ethical issues related to communication.

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[15] For a discussion of the role of contestation in human rights diplomacy and human rights practice more generally, see G. Ulrich, 'Framework for the Analysis of Human Rights Diplomacy' in M. O'Flaherty, Z. Kedzia, A. Müller and G. Ulrich (eds), *Human Rights Diplomacy – Contemporary Perspective* (Martinus Nijhof/Brill 2011).

[16] Cf. G. Ulrich 2001 and 2003 (n 4). See also C.S. Molyneux, N. Peshu and K. Marsh, 'Understanding of Informed Consent in a Low-income Setting: Three Case Studies from the Kenyan Coast' (December 2004) 59 Soc Sci Med. 2547ff; and P.A. Marshall, *Ethical Challenges in Study Design and Informed Consent for Health Research in Resource-poor Settings*, WHO Special Topics No. 5, TDR/SDR/SEB/ST/07.1 (WHO 2007).

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It is from time to time questioned whether the requirement for informed consent applies in connection with research that is non-invasive and associated with only minimal risks of harm. In other words, are some research areas exempt from the standard of informed consent? A related set of questions has to do with the application of methodologies that are premised on detracting attention from the research situation and that therefore are deemed to be incompatible with explicit consent procedures. While there is no single authoritative answer to these questions, it may be suggested that the standard of informed consent should as far as possible be acknowledged as a mandatory requirement for all research involving the participation of human subjects, but that it in some circumstances may be justified to allow for a certain degree of flexibility with regard to the formality of application.[17]

Covert research

Special complications arise in connection with covert and contested research, i.e. in situations where researchers in effect are dissimulating, disguising or deflecting attention from the fact that they are conducting research. The two most common reasons for doing this are that the research agenda is expected to be met with opposition by participants or by authorities competent to grant research permission, and that the awareness of contributing to research is assumed to affect the manner in which research participants act and respond to questions and therefore to hamper the ability to obtain untainted and reliable research data. This is above all a concern in the behavioral sciences and in some social sciences as well as in research involving illegal or morally/socially controversial practices. In such situations, researchers sometimes seek to bypass informed consent procedures and may argue that the standard is not applicable. Or they may tailor the description of research methodologies and objectives to the given context and seek to disguise elements that might meet with opposition. A common motivation behind such dissimulation is a profound sense of mistrust towards authoritative review bodies and a concomitant sense of the importance of one's research and superiority of one's own moral integrity.

Such impulses should be approached with great caution. If standard consent and/or approval procedures are exceptionally to be waived in a

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[17] In the article 'Informed Consent, We Are Not Exempt' ((1994) 53 Human Organization 1), Carolyn Fluehr-Lobban argues against the characteristic adversity among social anthropologists to embrace the principle of informed consent on account of its apparent incompatibility with the method of participant observation, but she concedes that it may be legitimate to attain consent 'without forms'.

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given context, then two supplementary conditions must in the present author's view obtain. First, the research proposal and methodology must be reviewed and approved by a competent audit body in another setting – which is to say, in other words, that professional ethics cannot be construed merely as a matter of exercising private conscience. Secondly, the researchers should, as emphasized above, be attentive to the underlying rationale of the principle of informed consent and ensure that this is respected to the maximum degree possible in the given situation through complementary means.

DOING GOOD

Perhaps the most common connotation of the notion of ethics is to reach out and do good for others. The technical term for this is *beneficence*. Alongside the injunction not to do harm (*non-maleficence*) and the requirement to treat others with dignity and respect, the principle of beneficence must be recognized as a core parameter of ethical consideration. It features in one form or another as central to most schools of moral philosophy, notably utilitarianism, which in effect reduces all ethical reasoning to this single formula.

The sense of obligation to do good for others applies in immediate face-to-face relations and across vast distances (as when we feel obliged to contribute to disaster relief after natural disasters in faraway places), at a general societal level and in a more abstract sense to humanity at large. Some schools of thought, often associated with the notion of an 'ethics of care', recognize special responsibilities towards individuals with whom we are personally related (such as parents towards their children), but this is not a primary concern in the context of professional ethics where relations as a point of departure are anonymous. In everyday social interaction, the inclination to do good is associated with sentiments such as empathy, compassion and social responsibility. Conceptually, the act of doing good for others can be thematized as something *optional*: something we elect to do as a gesture of benevolence and charity, or it may have an *obligatory* character and be interpreted as a matter of responding to pre-existing moral or legal entitlements. In the latter sense it is intrinsically linked with notions of *social justice*.

Either way, beneficence is always at best an imperfect approximation of an ideal, as the good we can accomplish pales in comparison with existing needs. This is particularly true when it comes to large-scale need, mass violence, systemic deprivation and impoverishment – all of which pose requirements that vastly exceed the capacity and agency of any individual

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actor. The fulfillment of the obligation not to expose others to harm, by contrast, largely falls within our own control. While seemingly closely related and overlapping in many regards, the principles of beneficence and non-maleficence are therefore structurally and logically very different. The commitment to do good marks a positive rather than a negative aspiration. It is relative rather than absolute in nature, and the obligations deriving from it tend to be imprecisely defined.

Its inherent ambiguities notwithstanding, the principle of beneficence defines an essential point of inquiry in the context of research ethics. The capacity to conduct research as well as the access to infrastructure and data that this presupposes must be conceived as a public good and hence entail an obligation to make adequate use of available scarce resources and return something to society. It is, moreover, reasonable to insist that if a certain element of risk is to be accepted as an inevitable feature of research, then there had better be compelling positive reasons for accepting this – in other words reasonably well defined, likely positive outcomes of a given enterprise. A purist might argue that individual harm beyond a certain point is never justifiable by reference to a greater good, but as one can never be certain of outcomes, the weighing of probable risks and benefits is a standard element in virtually all *ex ante* ethical assessments.

The essential questions to ask at this level of ethical consideration in relation to research are:

- What are the expected benefits of the research?
- In what ways does the research contribute to scientific knowledge, and does it have foreseeable practical applications?
- Are the inconveniences and possible risks of harm proportionate with the benefits anticipated to be accrued from the research?
- Do the probable benefits justify the investments of time and resources in the proposed research? Are scarce public resources being used in a responsible manner?
- How are favourable outcomes likely to be distributed? Will they benefit the general public/humanity at large, or will they rather be reserved for particular communities, groups or individuals?

In probing such questions, it is relevant to distinguish between benefits that are *intrinsic* to the research and those which might be considered *incidental* outcomes. In terms of intrinsic benefits, research must as a point of departure always be expected to contribute to the enhancement of scientific knowledge. The research should be situated in a well-defined academic context, and it is incumbent on the researcher to elaborate specifically how the proposed study may enhance our understanding of the given subject

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matter. Further to this, research often aims at achieving practical outcomes in the form of technological advances or an improved ability to solve human and societal challenges.

Incidental beneficial outcomes, by comparison, may include raising awareness of pressing issues and advantageous practices, linking up people, developing capacity to tackle societal problems and, importantly, building local research capacity and laying the foundation for further studies in the same area.[18] Researchers, moreover, are often requested to assist people in the areas where research is being conducted in ways that are unrelated to the research itself. This may be a source of high, sometimes unrealistic, expectations and may place the researcher in an awkward dilemma in terms of how far to extend oneself beyond one's core engagements – as discussed above in connection with the notion of 'harm by omission'. It will often be deemed reasonable to make some returns to individual participants and host communities for their contribution to the given research, but to offer outright compensation for research participation should be approached with great caution as it may function as an undue incentive to research participation and hence as a source of implicit coercion which runs counter to the principle of free and voluntary consent. This is particularly a problem in connection with research in low-income countries or communities.[19]

Application in Relation to Human Rights Research

A characteristic feature of human rights research is that it sheds light on otherwise neglected problems and addresses the concerns of disadvantaged and marginalized social groups. This may in and of itself be regarded as an intrinsic benefit – an expression of the universalistic ethos of science in the context of social injustice.

In applying the general formula of beneficence to research in the area of human rights, a natural point of inquiry is to ask: *does the proposed research contribute to the promotion and protection of human rights?* It should of course not be assumed that human rights researchers subscribe

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[18] Hampering the possibilities to conduct future research in a given area, conversely, must be conceived as a matter of long-term harm. This is a not infrequent side effect of substandard research practice.

[19] The Commentary to CIOMS Guideline (n 2) number 7 contains a detailed and perceptive discussion of this issue, as does the Nuffield Council report (n 2), chapter 6. See also C.S. Molyneux, S. Mulupi, L. Mbaabu and V. Marsh, 'Benefits and Payments for Research Participants: Experiences and Views from a Research Centre on the Kenyan Coast' (2012) 13 BMC Med Ethics 1.

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uncritically to any agenda associated with human rights. Good science presupposes a propensity for self-criticism and a healthy dose of scepticism *vis-à-vis* established doctrine. This must be applied to the human rights idiom itself and should to some extent inform all human rights research. However, even so, the international human rights framework, while open to contestation, is the closest one can come to a universal authoritative standard for qualifying the general good, and in this sense it constitutes a relevant point of reference for all professional activity, including research. This, indeed, may be seen as a primary example of how the human rights paradigm in important ways can inform and enhance the general discourse on professional ethics.

COLLABORATION ISSUES

In professional contexts related to civil service,[20] public administration and legal practice,[21] among others, the notion of ethics tends to be narrowly associated with an obligation to not abuse office.[22] This applies, for example, in relation to procurement and employment practices or when lawyers and judges recuse themselves from involvement in cases in which they may be partial or may be suspected of having a conflict of interest. The essential requirement, which in fact applies to anyone with significant professional decision-making responsibilities, is to disclose any possible conflicts of interest and avoid unduly benefitting from decisions taken in one's professional capacity or privileging individuals to whom one is related.

It is important to underline that this general requirement does not imply a ban on self-interested conduct. Quite the contrary, the presumption governing professional ethics is that it is normal and legitimate to pursue personal interests. The ethical requirement is merely that this must be done in a transparent fashion and without unduly compromising the interests

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[20] See, e.g. *Standards of Conduct for the International Civil Service*, adopted by the International Civil Service Commission (1954, most recently revised in January 2002) <http://icsc.un.org/resources/pdfs/general/standardse.pdf> accessed 20 May 2016.

[21] See, e.g. the American Bar Association *Model Rules of Professional Conduct* (1983, most recently revised in February 2013) <http://www.americanbar.org/groups/professional_responsibility/publications/model_rules_of_professional_conduct.html> accessed 20 May 2016.

[22] Interestingly, the UN Ethics Office's resources materials on 'Ethics Advice and Guidance' are almost exclusively devoted to issues of this nature <http://www.un.org/en/ethics/standvalue.shtml> accessed 20 May 2016.

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of others. This level of ethical consideration, therefore, is fundamentally about managing and negotiating vested interests while ensuring transparency, propriety and equity (or fairness) in professional conduct. The same basic outlook is reflected in anti-corruption and good governance agendas at the societal level.

In the academic arena, the issue of equity notably arises in relation to questions about how relations of collaboration are defined, who gets credit for research results and recognition of authorship and the degree to which different parties benefit materially and professionally from their involvement in the given scientific endeavour. Most research is in one sense or another a collaborative effort, and upon examination it is not uncommon to find that some members of a research team harbour misgivings about being misrecognized and unfairly treated, perhaps outright discrimination. Implicit tensions related to the terms of collaboration may be further fuelled by the fact that most research is embedded in hierarchical structures and shaped by differences in title and status, differences in experience and understanding of the given subject matter, differences in access to funding and research permission, and, on account of all of these differences, disparities in recognition and reward.[23] Such disparities may be ethically justifiable, but to establish this they are subject to a test of non-discrimination, equity and a reasonable degree of openness and inclusiveness in the negotiation of terms – even when set in markedly hierarchical structures. In effect, this means applying a high standard of communication ethics within the research team itself, which in turn may be expected to enhance the prospect of successful scientific outcomes.

Given that this level of ethical consideration applies to professional conduct irrespective of the subject area, it has no special implications for research in the area of human rights. It may be noted, however, that the principles of equity and non-discrimination, like the related principles of transparency and good governance, are integral to the ethos of human rights and should be rigorously honoured in this research context.

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[23] When conducting fieldwork on ethical problems in donor-sponsored research in developing countries (cf. n 3), the present author was repeatedly confronted with the perception that foreign researchers, owing to their privileged funding access, lead in developing research protocols and perception of superior scientific competences, unfairly privilege their own agendas and in effect treat local collaborators as inferior. Whether or not fully justified, such perceptions are indicative of an ethical issue in urgent need of attention. However, it is only very sporadically addressed, if at all, in most ethics guidelines. The Norwegian *Guidelines for Research Ethics in the Social Sciences, Law and the Humanities* (n 2) touch upon ethical considerations related to research collaboration in Section D of the guidelines.

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PROFESSIONALISM AND GOOD SCIENTIFIC CONDUCT

A fifth and final parameter of ethical consideration has to do with compliance with standards of good scientific conduct. This includes anti-plagiarism norms, academic honesty and a general requirement for methodological stringency, accuracy in the recording of research data, caution about generalizing findings pertaining to particular cases, and ensuring that empirical findings can be tested and verified or falsified, as the case may be.

Such norms can in most cases be linked with another level of ethical consideration. The falsification of research findings may thus be an immediate cause of harm; plagiarism, in a generalized sense, violates norms of equity in research cooperation; and sloppy methodology detracts from the ability of research to enhance scientific knowledge and contribute to a greater social good, etc. It nevertheless makes sense to group them together under a separate heading, as they reflect a general requirement to conduct oneself in accordance with the knowledge base and established procedures of the profession and (unless there are compelling reasons to the contrary) in compliance with the fundamental values, procedures, and objectives of the employing entity.[24]

ETHICS IN THE RESEARCH CYCLE

Taking into account the full range of relevant considerations as elaborated in the present chapter, the question of ethics requires attention throughout the entire research process. The following paragraphs provide an indication, summarized in Table 9.1, of the types of issues that typically need to be considered at different stages of research.

Planning the Research

Research proposals in some academic disciplines are required to include an explicit and detailed ethics section. It is suggested that this standard should be adopted for all human rights research irrespective of academic discipline.

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[24] The *Code of Conduct for OHCHR staff* (n 6), thus places strong emphasis on compliance with organizational rules and procedures and on displaying allegiance to the objectives of the UN. The same ethos characterizes the *Standards of Conduct for the International Civil Service* (n 20).

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Table 9.1 Ethics in the research cycle

	Initial phase Project planning and design	Preparation phase	Implementation phase Data collection and analysis	Completion phase Dissemination and operationalization of results
No harm issues	Identify risks of harm. Plan for how to react in case of negative developments.	Alert research collaborators and participants to possible risks of harm, including harm perpetrated by others as a consequence of research activities.	Carefully monitor effects of the on-going research activity with regard to direct and indirect harmful outcomes.	Monitor reactions to the publication of results. Beware of long-term adverse consequences of published research findings.
Communication issues	Adopt policy on informed consent and plan for how research aims and methodologies will be communicated to stakeholders.	Communicate research methodologies and aims to prospective research participants and other relevant stakeholders. Obtain informed consent, as required.	Maintain respectful interaction with research participants. Monitor and respect willingness of research participants to continue their involvement. Treat sensitive information with discretion.	Ensure adequate feedback on research outcomes to individuals and groups who have contributed to the research. Beware of humiliating or degrading portrayal of individuals or groups implicated by the research.

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Beneficence issues	Elaborate expected benefits of the research. Ensure proportionality between likely beneficial outcomes and any risks of harm or other inconveniences linked with the research.	Negotiate incidental benefits with participants and stakeholders.		Seek, as far as possible, to maximize the impact and benefits of the research and ensure equitable access to research outcomes.
Collaboration issues	In collaborative research, be as inclusive as possible in defining methodologies and objectives, responsibilities and authorship, etc.	Openly discuss and reach agreement on terms of collaboration within research team.	Monitor perceptions of equity within the research team; broach issue as required.	Ensure equitable recognition for research outcomes.

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The development of a research initiative should as a matter of course involve taking stock of and making a statement about ethical implications, including possible risks of harm and anticipated benefits, whether and how informed consent will be obtained, and safeguards in case of unforeseen complications. Such an *ex ante* ethics analysis serves a dual purpose. It provides assurance that the relevant ethical considerations have been taken into account in the planning of the research and it may subsequently serve as a point of reference for ethical monitoring and accountability.[25]

Obtaining Research Permission

Research proposals may be subject to multiple levels of review: initially by funding agencies and the home institution(s) of the lead researcher(s) and subsequently by review boards in the location or locations where the research will be conducted. The authority of each such review body should in principle be respected and given equal weight. However, complications arise in cases where a given research agenda is supported by the sponsoring institution(s) but is for one reason or another considered controversial in the context in which the research is to be carried out. This may prompt researchers to adapt the manner in which methodologies and objectives are described and in some cases submit alternative versions of their project description to the different review bodies – sometimes even with the tacit knowledge of the funding agency. This is typically justified by the greater good that the research is committed to advancing. While partially understandable, such dissimulation is fundamentally problematic, not least because it undermines the authority and effectiveness of local review structures. It moreover runs counter to the commitment to honesty and openness that ought to characterize human rights research.

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[25] It may be noted that the request for an ethical assessment prior to commencing research bears a close affinity to what in the context of project planning is known as *ex ante Human Rights Impact Assessment*, and likewise to the notion of *Human Rights Due Diligence* as envisioned in the UN *Guiding Principles on Business and Human Rights*, prepared by John Ruggie and adopted by the Human Rights Council in 2011 (A/HRC/17/31, 21 March 2011) <http://www.ohchr.org/Documents/Publications/GuidingPrinciplesBusinessHR_EN.pdf> accessed 20 May 2016. The fact that these compliance mechanisms have gained widespread support within the human rights community should serve as impetus to also subscribe to a rigorous ethical review standards for research in the area of human rights.

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Preparation Phase

The initial stage of planning and setting up the research is typically the moment when relations of collaboration are defined. This should be taken as an opportunity to broach potentially divisive, competing claims to recognition and reward. A candid ethics discussion at this stage may also help research collaborators to develop a common perspective on key ethical decisions, policies and issues in need of subsequent attention. In conjunction with the preparation of eventual field visits and interviews, a plan should be made for how research objectives, methodologies, and possible risks or other inconveniences will be communicated to the relevant stakeholders.

Implementation Phase

Once up and running, most scientific engagements (except when entirely restricted to desk research) will involve an important element of interaction with individuals and groups contributing to the research in different capacities. This requires attention to the common standards of respectful interaction; attentiveness to tensions, sensitivities and vulnerabilities in the given area; and a careful monitoring of effects and consequences of the research, in particular with regard to possible direct or indirect harm. Sensitive research data must be carefully protected and confidentiality safeguarded. On-going cooperative research should also involve an intermittent stocktaking of how the terms of collaboration are being perceived by the parties involved.

Completion Phase

Upon completion of a given scientific engagement, it is ethically incumbent on the lead researcher(s) to ensure a reasonable degree of follow up with the involved parties; to award credit and recognition of authorship to collaborators, as appropriate; to refrain from stereotyping and unwarranted derogatory portrayals of particular individuals or groups; to remain attentive to possible long-term harmful impacts; and, on a more positive note, to actively disseminate results and seek to maximize possible benefits accruing from the research while striving, as far as possible, to ensure equity in the enjoyment of beneficial outcomes.

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A CONCLUDING PERSPECTIVE: CONTEXTUALIZING ACCOUNTABILITY

The overriding focus of the present chapter has been on identifying ethical considerations of relevance to research and articulating specific obligations at each level of consideration. Against this background it is naturally asked, how are the relevant ethical norms enforced and what can be done to ensure a reasonable degree of ethical accountability?

To broach these questions, it must be noted that different norms are subject to different forms of monitoring and enforcement. Norms related to the prevention of harm, formal consent procedures and the avoidance of blatant conflicts of interest, for example, may be monitored by externally appointed review boards and are in many cases subject to formal appraisal in advance of commencing the research. Other norms, such as the obligation to display sensitivity to the life situation of research participants or to ensure proportionality between contributions and benefits deriving from the research, require attention throughout the research cycle and in the concrete settings in which the research is conducted. They tend to be less precisely defined and cannot be 'cleared' in advance of the research in the manner of a checklist approach.

This speaks to the question of how to understand accountability.[26] At one level ethical accountability is exercised by monitoring bodies that have been established with a mandate to oversee scientific and professional practice and with the ability to impose sanctions in the case of serious compliance failures. Ethical accountability on this interpretation has a quasi-judicial character. In another (complementary) sense, accountability must be recognized as an integral feature of real-life communicative interaction, and hence also as integral to the research process itself. In this sense it involves responding to uncertainties and legitimate concerns on the part of a broad range of stakeholders involved in or affected by the research.[27] These two basic modalities of accountability may be described, respectively, as *hard* and *soft* accountability. Ethics requires an element of both. Some issues are so grave that they call for external monitoring with adequate enforcement power, but not all relevant ethical requirements are

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[26] For a wider discussion of accountability in research ethics, see G. Ulrich 2011 (n 4).

[27] Robert Gibbs's *Why Ethics? Signs of Responsibilities* (Princeton University Press 2000) contains a highly insightful and challenging analysis of the concept of *responsibility* and its inherent affinity to a readiness to respond to legitimate concerns in face-to-face interaction with interlocutors and (by implication) parties affected by professional conduct.

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amenable to enforcement through coercive means. They rather display an interactive, reciprocal character.

Accountability does not flourish in a vacuum. It is by its very nature always *situated*, i.e. embedded within determinate structures which may be characterized as 'sites of accountability'. Ethics review boards at both national and institutional level naturally fulfill this function, but so do a range of other entities such as funding agencies, publishing houses, the public media, and self-appointed watchdog agencies. An element of ethical monitoring and accountability also continually unfolds in relations among peers and in the interaction between scientists and research participants or between scientists and the local communities hosting research.

To strengthen ethical standards in a given research area, scientists need to engage constructively with demands for both hard and soft accountability in multiple contexts. This requires not only goodwill but also that the relevant accountability structures are functional. Scientists, in other words, must be met with qualified and credible requests for an elaboration of the ethical implications of their proposed or on-going activities and must be held responsible in an appropriate and meaningful fashion when things go wrong. Where requests for accountability are lacking, insufficiently informed or governed by extraneous motives, the respect for ethical review procedures tends to atrophy. Requests for accountability are then perceived as a vehicle of external control and practitioners naturally gravitate towards treating ethics first and foremost as a matter of personal conscience.[28] This undermines the standing of professional ethics as a legitimate and crucially important public concern.

What is essential in the present author's view is to frame an approach to ethics that does not from the outset focus on misconduct, thereby placing researchers in a defensive position *vis-à-vis* requests for accountability. If the very fact of encountering ethical problems is treated as an indication of acting irresponsibly and in bad faith, then scientists and other professionals will naturally resist any form of situated accountability and perceive ethics as an unwelcome interference with their otherwise important and well-intended activities. To overcome such resistances, an element of ambiguity and candid disagreement about what constitutes the correct course of action in a given situation needs to be accepted as an integral dimension of healthy ethical discourse. Only in exceptional cases do ethical

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[28] For a discussion of this and related issues, see P. Pels, 'Professions of Duplexity: A Prehistory of Ethical Codes in Anthropology'; and G. Ulrich, 'Comment to Peter Pels "Professions of Duplexity"' (1999) 40 Current Anthropology 101, 126–127. See also M. Strathern (ed.), *Audit Cultures: Anthropological Studies in Accountability, Ethics and the Academy* (Routledge 2000).

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failures genuinely compromise the character and professional integrity of the protagonist. For the most part, uncertainties are legitimate and in fact indicative of a reflexive approach to one's research and a sincere commitment to responsible professional conduct. The forging of spaces to address such uncertainties will help to foster 'good science' in both a normative and an academic sense.

REFERENCES

American Anthropologist Association, 'Statement on Ethics' <http://ethics.americananthro.org/category/statement/> accessed 20 May 2016

American Bar Association, *Model Rules of Professional Conduct* (1983, revised February 2013) <http://www.americanbar.org/groups/professional_responsibility/publications/model_rules_of_professional_conduct.html> accessed 20 May 2016

Anderson, M.B., *Do No Harm: Supporting Local Capacities for Peace Through Aid* (Local Capacities for Peace Project, Collaborative for Development Action 1996)

Beauchamp, T.L. and J.F. Childress, *Principles of Biomedical Ethics* (6th edn, OUP 2008)

Clifford, J. and G. Marcus, *Writing Culture: The Poetics and Politics of Ethnography* (University of California Press 1986)

Council for International Organizations of Medical Science, *International Ethical Guidelines for Biomedical Research Involving Human Subjects* (2002)

Fluehr-Lobban, C., 'Informed Consent, We Are Not Exempt' (1994) 53 Human Organization 1

Geissler, P.W., and R. Pool, 'Popular Concerns about Medical Research Projects in sub-Saharan Africa – A Critical Voice in Debates about Medical Research ethics' (July 2006) 11 Tropical Medicine and International Health 975ff

Gert, B., *Morality: A New Justification of the Moral Rules* (OUP 1988)

Gert, B., C.M. Cluver and K.D. Clouser, *Bioethics: A Return to Fundamentals* (OUP 1997)

Gibbs, R., *Why Ethics? Signs of Responsibilities* (Princeton University Press 2000)

International Civil Service Commission, *Standards of Conduct for the International Civil Service*, adopted by the United Nations General Assembly (1954, revised 2013) <http://icsc.un.org/resources/pdfs/general/standardse.pdf> accessed 20 May 2016

Jonson, A.R., *A Short History of Medical Ethics* (OUP 2000)

Marsh, H., *Do No Harm: Stories of Life, Death and Brain Surgery* (Weidenfeld & Nicolson 2014)

Marshall, P.A., *Ethical Challenges in Study Design and Informed Consent for Health Research in Resource-poor Settings*, WHO Special Topics No. 5, TDR/SDR/SEB/ST/07.1 (WHO 2007)

Molyneux, C.S., N. Peshu and K. Marsh, 'Understanding of Informed Consent in a Low-Income Setting: Three Case Studies from the Kenyan Coast' (December 2004) 59 Soc. Sci. Med. 2547ff.

Molyneux, C.S., S. Mulupi, L. Mbaabu and V. Marsh, 'Benefits and Payments for Research Participants: Experiences and Views from a Research Centre on the Kenyan Coast', (2012) 13 BMC Med Ethics 1

National Committees for Research Ethics in Norway, *Guidelines for Research Ethics in the Social Sciences, Law and the Humanities* (2006)

Nuffield Council on Bioethics, *The Ethics of Research Related to Healthcare in Developing Countries* (2002)

O'Flaherty, M. and G. Ulrich (eds), *The Professional Identity of the Human Rights Field Officer* (Ashgate 2010)

O'Flaherty, M., Z. Kedzia, A. Müller and G. Ulrich (eds), *Human Rights Diplomacy – Contemporary Perspective* (Martinus Nijhof/Brill 2011)

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Pels, P., 'Professions of Duplexity: A Prehistory of Ethical Codes in Anthropology' (1999) 40 Current Anthropology 101
Perry, G., *Behind the Shock Machine: The Untold Story of the Notorious Milgram Psychology Experiments* (The New Press 2013)
Posner, G.L. and J. Ware, *Mengele: The Complete Story* (McGraw-Hill 1986)
Resnik, D., 'What is Ethics in Research and Why is it Important?' (2011) 8 National Institution of Environmental Health Sciences <http://www.niehs.nih.gov/research/resources/bioethics/whatis/> accessed 20 May 2016
Reverby, S.M., *Examining Tuskegee: The Infamous Syphilis Study and its Legacy* (University of North Carolina Press 2009)
Said, E., *Orientalism* (Vintage Books 1979)
Shamoo, A. and D. Resnik, *Responsible Conduct of Research* (2nd edn, OUP 2009).
Smith, C.M., 'Origin and Uses of Primum Non Nocere – Above All, Do No Harm!' (2005) 45(4) J Clin Pharmacol 371ff
Strathern, M. (ed.), *Audit Cultures: Anthropological Studies in Accountability, Ethics and the Academy* (Routledge 2000)
Turnbull, C., *The Mountain People* (Simon & Schuster 1972)
Ulrich, G., 'Comment to Peter Pels "Professions of Duplexity"' (1999) 40 Current Anthropology 126–127
Ulrich, G., 'Optimum Ethical Standards', in 'Proceedings Seminar on Health Research Ethics in Africa' (January 2001) 78 (Supp. 1) Acta Tropica 1
Ulrich, G., 'Charges and Counter-Charges of Ethical Imperialism: Towards a Situated Approach to Development Ethics' in Ph. Q. van Ufford and A.K. Giri (eds), *A Moral Critique of Development: In Search of Global Responsibilities* (EIDOS, Routledge 2003)
Ulrich, G., 'The Statement of Ethical Commitments of Human Rights Professionals: A Commentary' in M. O'Flaherty and G. Ulrich (eds), *The Professional Identity of the Human Rights Field Officer* (Ashgate 2010)
Ulrich, G., 'Framework for the Analysis of Human Rights Diplomacy' in M. O'Flaherty, Z. Kedzia, A. Müller and G. Ulrich (eds), *Human Rights Diplomacy – Contemporary Perspective* (Martinus Nijhof/Brill 2011a)
Ulrich, G., 'Elucidating Ethics in Practice – Focus on Accountability' in P.W. Geissler and S. Molyneux (eds), *Evidence, Ethos and Experiment: The Anthropology and History of Medical Research in Africa* (Berghahn Books 2011b)
United Nations, 'International Covenant on Civil and Political Rights', G.A. res. 2200A (XXI), 21 U.N. GAOR Supp. (No. 16) at 52, U.N. Doc. A/6316 (1966), 999 U.N.T.S. 171, entered into force 23 March 1976
United Nations, OHCHR, Code of Conduct for OHCHR staff, Directive No. 2 (1999). Reproduced in 'Norms Applicable to UN Human Rights Officers and Other Staff', *Training Manual on Human Rights Monitoring* (OHCHR, 2001), pp. 449–464
United Nations, *Guiding Principles on Business and Human Rights*, prepared by John Ruggie and adopted by the Human Rights Council in 2011 (A/HRC/17/31, 21 March 2011) <http://www.ohchr.org/Documents/Publications/GuidingPrinciplesBusinessHR_EN.pdf> accessed 20 May 2016

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