HUMAN RIGHTS AT SEA

RESEARCH ETHICS POLICY

First Edition September 2015

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1. INTRODUCTION

While the academic community has been acutely aware of the importance of **Research Ethics** since the middle of the 20th Century, recently there has been a drive to raise awareness of the ethical component of research. This movement can be felt particularly in the EU where the newly launched legislative controlled **7th Framework Programme** sets out an ethical review procedure which must be explicitly addressed before research proposals can be considered for funding.

However, the renewed emphasis on Research Ethics is due to more than the EU. Research Ethics in the international sphere have always had a strong connection to Human Rights, and the global focus on Human Rights Conventions has had a very positive impact on the status of Research Ethics. This **Human Rights-led approach** is also helping to dramatically increase the scope of the discourse, especially in relation to data protection and the consent of any individuals affected. Both of these elements are now at the heart of modern Research Ethics, and must be addressed in any meaningful discussion of the subject.

Making **ethics** an integral part of a research proposal is an increasingly important way to maintain professional standards and ultimately improve the quality of the final research. But it need not be an arduous process. In this policy document, we will first briefly address the legal and historical basis for Research Ethics, before exploring the modern European Research Ethics framework and its implications. Finally, we will look at specific examples of how Research Ethics can impact work, and cover some key rules to bear in mind when starting a new project.

2. THE HISTORY AND LEGAL BASIS OF RESEARCH ETHICS

Since their inception, Research Ethics have always had a distinctly international character. The first code of conduct was established in the aftermath to the Nuremberg Trials and was built upon by the World Medical Association in the Declaration of Helsinki. While this declaration was not binding in itself, it has formed either the basis or main influence for all subsequent international legal documents. This effect is so pronounced that the Nuremberg code, as expounded by the Declaration of Helsinki, has been described as the cornerstone for international Research Ethics.

While many organisations have developed their own specialised guidelines, such as the British Council for Education's 'sociological research guidelines', it remains important to investigate the Nuremberg Code in greater detail, as it is the basis of all Research Ethics.

2.1 THE NUREMBERG CODE

The Nuremberg Code was formulated by American judges at the Nuremberg Trials as a response to the atrocities that they uncovered during the course of proceedings. As a result of the motivation for their creation, the rules are explicitly aimed at medical research. There are only ten rules, all of which are left at a high level of abstraction in order to be universally acceptable and applicable. The rules are focussed on the issues of **consent**, **proportionality**, and **necessity**, with the **right to withdraw** at the core of the document.

Despite the vague nature of the text, the Nuremberg Code gained its place in history because it is a rights focussed document, unlike its predecessors. This granted inviolable rights to the individual rather than requiring safeguards on the part of the practitioner. While this concept is far less alien to us after the Human Rights revolution, at the time it was a completely different approach to Research Ethics, or indeed ethics generally. Despite its non-binding character, the rights-based approach and basic framework set out in this document has been followed by every formulation of Research Ethics that has followed.

2.2 THE EUROPEAN CHARTER OF FUNDAMENTAL RIGHTS

In addition to the international documents specific to Research Ethics, ever since the Nuremberg Code there has been a strong link between Research Ethics and Human Rights. The link was explicitly referenced by the Oviedo Convention, a Convention for Medical and Bio-medical Research Ethics, as well as the EU Research Ethics Guidelines (see page 12 for sources). Both documents borrow heavily from the language of International Human Rights jurisprudence and emphasise the academic community's commitment to the Human Rights approach and structure.

Human Rights are considered particularly important in the European Union, where Research Ethics is firmly based on the European commitment to Human Rights across all policy areas. This approach has been enshrined into the European legislative framework through the European Union's own Human Rights document, the European Charter of Fundamental Rights, which was incorporated by the Lisbon Treaty.

The Charter set out a number of principles to which all European Union institutions and legislative texts are required to conform, including those involved in Research Ethics. This means that the Charter is an essential cornerstone for any Research Ethics within the European Union and, due to the approach taken in the international Research Ethics conventions listed above, the Charter can also be taken as a good guide for ethical research generally.

The following provisions in particular may be relevant in the context of academic research, and will be examined further in the Ethical Issues section below.

Article 7 – Respect for private and family life

- Everyone has the right to respect for his or her private and family life, home and communications.

Article 8 – Protection of Personal Data

- Everyone has the right to the protection of personal data concerning him or her.
- Such data must be processed fairly for specified purposes and on the basis of the consent of the person concerned or some other legitimate basis laid down by law. Everyone has the right of access to data which has been collected concerning him or her, and the right to have it rectified.
- Compliance with these rules shall be subject to control by an independent authority.

Article 13 – Freedom of the Arts and Sciences

- The arts and scientific research shall be free of constraint. Academic freedom shall be respected.

3. ETHICAL ISSUES

3.1 DATA PROTECTION AND PRIVACY

The Charter of Fundamental Rights within the EU has, recently reaffirmed the importance of data protection and the right to privacy. This document makes privacy and data protection fundamental rights that must be protected by both EU legislative actions and institutions. However, these are not issues that are limited to the Human Rights sphere. Both data protection and privacy are frequently mentioned in international Research Ethics treaties as far back as the Oviedo Convention.

Clearly both issues are at the heart of Research Ethics, and so before exploring how to manage the dilemma they present it is worth examining the scope of each term. **Privacy** in this context is generally treated as having two distinct limbs: the right to maintain control over personal information and communications; and the right to have personal information treated confidentially if it is disclosed (see page 12 for details). **Data protection**, on the other hand, is the framework and system designed to protect our right to privacy – protecting personal data from unintended or malevolent use.

In the context of research, both of these issues arise whenever personal data is collected and stored. It is also important to note that personal information in this context can include health information, financial, or travel information, as well as personal details about behaviour or family composition.

The main challenge for researchers is to find ways to make the most effective use of the data collected, but at the same time ensure that all identifiable information is protected to guarantee the privacy of the research subjects.

The main legislation in this area is currently the **Data Protection Directive** where the key principle is **proportionality**. This in turn is broken down into three essential questions:

- Is all the data collected necessary to conduct the research?
- Is all the personal data collected adequate and relevant?
- Has the data been anonymised as far as possible?

It is very important that whenever a research project involves handling personal data, all of these issues are addressed. Particularly important is the issue of necessity that must be judged on a case-by-case basis, as well as that of **anonymization**. For data to have been properly anonymised it must not be possible to link the data back to the individual in any way. Alternatively, it is possible to codify data so that the most obvious personal data, such as names and addresses, is replaced with a code.

3.2 INFORMED CONSENT

Informed consent has also been regarded as one of the most important principles in Research Ethics by many international conventions, including the Nuremberg code. Whilst much of the literature is understandably based around medical Research Ethics, there are several key principles that are equally applicable to the context of social research.

These principles can be broken down into three areas:

- the state of the volunteers,
- the nature of the information provided, and
- the manner in which they are informed.

Any participants in a research project clearly need to be capable of truly consenting to the study. This means that they need to be sufficiently mentally competent to understand the nature of the research, and be acting entirely voluntarily – free from any actual or potential duress.
Participants should be clearly informed of:

- research goals;
- possible adverse consequences;
- experimental procedure;
- all risks and benefits expected to occur;
- any insurance guarantees, and
- possibilities to refuse or withdraw.

In addition, great care must be taken with the manner in which participants are informed. It is crucial that the individuals concerned fully realize the impact of the research at the time they consent. In order to ensure this is the case, good practice can require a presentation on the research project, including its goals and objectives, or conducting interviews to explain what will happen with the research and data at the end of the project.

3.3 RESEARCH INVOLVING DEVELOPING COUNTRIES

It is important to be aware that even when research is occurring outside the European Union, EU legal principles do not stop applying. In addition, the researcher must also comply with the relevant national legislation in the country where the research is taking place, as well as any applicable international standards such as the Human Rights Conventions referenced earlier in this document.

The issue of informed consent is heightened when researching in different countries, and particular care must be taken to obtain consent from potentially vulnerable populations. Specifically, the researcher should be aware of cultural differences, economic and linguistic barriers, and levels of education.

4. CORE FRAMEWORK

Every research project is different, and throws up its own set of ethical dilemmas. While there is no substitute for personal reflection and criticism during the course of the research, the following framework may help to guide that thought process at the various key stages of any research.

4.1 RESEARCH AS A FIELD OF STUDY AND PRACTICE

At the core of ethically responsible research are the principles of **openness**, **criticism** and **respect for all scientific perspectives**. To this end, there are a number of good practices that researchers should bear in mind at all times, but especially while planning or proposing research:

- Researchers can be expected to work on the basis of scientific correctness alone, without discrimination on the basis of scientifically irrelevant factors such as age, sex, sexual preference, ethnicity, language, religion or political affiliation.
- Researchers must be aware that their work can influence and impact society, and that any assumptions made during the course of their research can have a potentially damaging effect. As a result, researchers must be careful to acknowledge any assumptions made in the course of the research, and to ensure that no assumptions are ever presented as indisputable truth.
- In order to maintain the highest professional standards, researchers must be as unbiased as possible and be careful not to conceal any influences or ideological positions where relevant.

4.2 RESEARCH PROCEDURE

Once the research is actually underway the most dominant principles shift towards those surrounding **data protection** and **professionalism**:

- Researchers should keep records of, and be prepared to disclose, the methods by which they conduct their research as well as the general sources of their data.
- The security, anonymity, and privacy of research subjects and informants should be respected rigorously in both quantitative and qualitative research.
- Any sources of personal information obtained by researchers should be kept confidential, unless the informants have asked or agreed to be cited.
- The consent of research subjects and informants should be obtained in advance. Covert research should be avoided in principle, unless it is the only method by which

information can be gathered, and/or when those in power obstruct access to the usual sources of information.

- Should informants be easily identifiable, researchers should remind them explicitly of the consequences that may follow from the publication of the research data and outcomes.
- Researchers should refrain from claiming expertise in fields where they do not have the necessary depth of research knowledge, especially when contributing to public discussion or policy debate.
- Funds provided for research must be used only for the agreed purpose.

4.3 PUBLICATION AND COMMUNICATION OF DATA

Once the research itself is finished, the ethical issues to consider become those of proper attribution and intellectual property rights:

- The contribution of scholars, sponsors, or other collaborators who have made a substantial contribution in carrying out a research project should be acknowledged explicitly in any subsequent publication.
- Data gathered in research activities and research work constitute the Intellectual Property of the Human Rights at Sea Charity which is in principle also entitled to Copyright.

5. CONCLUSIONS

This document has endeavoured to demonstrate that there is more to Research Ethics than the difference between what is within the letter of the law. Maintaining professional and ethical standards requires independent evaluation of the research project and any potential risks. In addition, the researcher themselves must remain aware of their research objectives whenever they are collecting data or interacting with the public, as well as considering the possible impact of the research on the wider society.

As has been discussed, the most important and common ethical issues in research are privacy and data protection, the involvement of vulnerable people, and research involving developing countries. While there are safeguards that can be built into the initial plan for the research, all of these issues require ongoing caution in order to prevent any unnecessary risks.

When in doubt, there are a number of specialist guides available, some of which are referenced in the bibliography below by way of example, as well as numerous international treaties to help guide and protect potential research. However, just as important as institutional framework, is the attitudes and behaviour of individual researchers. As was mentioned at the start of this document it is important to keep an internal reflexive attitude to any developments.

5.1 GOLDEN RULES FOR ETHICAL RESEARCH CONDUCT

- **Try to integrate ethical safeguards into your research projects from the first plan –** the vast majority of ethical issues can be dealt with easily with a little preparation. Being able to demonstrate an awareness of the ethical concerns in a research project is an essential pre-requisite to obtaining funding or academic recognition, especially at EU level.

- **Use existing codes of conduct for researchers** – there is a wealth of material available. Especially when the research is in a new or unfamiliar area, checking existing guides can flag up potential risks that may not have been obvious from the outset.

- **Do not hesitate to seek advice** – as the adage goes, it is always better to be safe than sorry. No one will criticise you for double-checking a concern and you may catch a potential problem before it materialises.

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HUMAN RIGHTS AT SEA

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Human Rights at Sea is a Registered Charity in England and Wales, No. 1161673
ISBN: 978-0-9932680-4-5