

WORKSHOP REPORT

**Ethical Protocols
and Standards for Research
in Social Sciences Today**

BRUSSELS, 11 JUNE 2015



**SCIENCE
EUROPE**
Social Sciences
Committee

Workshop on Ethical Protocols and Standards for Research in Social Sciences Today



Introduction

Science has always had to address ethical issues, with advances in science continuously creating new ethical challenges. Biomedical sciences have traditionally been viewed as the most developed in addressing ethics. The 1964 'Declaration of Helsinki'¹ was an effort to codify ethical approaches in biomedical experimentation, and has since provided the basis for the majority of subsequent documentation on the topic.

Research in the social sciences regularly faces its own ethical issues, yet it lacks an equivalent codification of approaches that are tailored to its disciplines, as well as sufficient infrastructures at the institutional level to assess proposals. The importance and value of ethics in social sciences research are not yet universally embraced, creating divergence in approaches and resourcing between countries, institutions and disciplines. Furthermore, social sciences research is undergoing a period of rapid change. There is increasing participation in multidisciplinary projects, while changes in technology are creating new challenges for social sciences researchers,² which need to be addressed.

The social sciences urgently need ethical protocols that can function effectively across disciplines and can adapt to advances in research methodologies and strategies. The Declaration of Helsinki is aimed squarely at physicians and biomedical researchers, and makes no provisions for ethical considerations regarding, for example, research in geographical areas that are under an oppressive regime or are in conflict, research with subjects who are in a vulnerable position, or the sometimes necessary use of deception as part of the research methodology. The Declaration's statement on privacy and confidentiality is simply the short message that "every precaution must be taken" to this effect; however, a growing number of studies based on 'Big Data' analyses raises potential ethical concerns over data sharing, data linkage, data re-identification and privacy issues, including the 'right to erasure'.³ This makes the need for a solid, robust code of ethics adapted to social sciences research increasingly pressing.

With this in mind, the Science Europe Scientific Committee for the Social Sciences organised a workshop to explore ideas on how to move this issue forward and how to proceed with establishing an ethical framework for the social sciences.

Workshop Aims

The specific aims of the workshop were to:

- ▶ identify the existing needs for an ethical framework within the social sciences research community and to consider the current status of ethical approaches in the various European countries;
- ▶ discuss the best way to establish an ethical framework for the social sciences as a whole; and
- ▶ give momentum to the wider discussion on creating such an ethical framework.

This was done by bringing together approximately 30 stakeholders to discuss ethics in social sciences. This predominantly comprised experts from Science Europe Member Organisations, but also included representatives from the European Research Council (ERC), the European Commission and UNESCO, as well as a number of researchers and members of the Social Sciences Committee of Science Europe.

Through presentations by researchers involved in projects with strong ethical components and from representatives of research institutions who deal with ethics on a daily basis, participants learned of a number of ethical issues, of approaches to managing risks, of developments in this area, and of the status of ethics approaches at national and European levels. These served as fuel for both plenary and break-out sessions, where participants discussed ideas of how to help embed ethics throughout social sciences research and establish a common framework.

In an introductory 'tour de table', attendees shared what they saw as the most pressing issues and explored potential approaches to help embed ethics throughout social sciences research. During the session, participants agreed that the debate underpinning the development of good practice guidelines for the research community in this area will have a substantial impact. They also agreed that, in comparison with other disciplines, the study of society at large today demands a deeper understanding of research approaches and theoretical frameworks determined by given research interests.⁴



Pressing Issues

Mr Isodoros Karatzas, Head of Sector, Ethics and Research Integrity at DG Research and Innovation, European Commission, provided insights from eight years of experience of ethics reviews in EU projects. He stressed the importance of social sciences developing an independent set of ethical standards, resulting in essence in a 'Helsinki'-type declaration specifically addressing the needs and challenges of social sciences. This would address what he called "the tyranny of the biomedical model"; in other words, a set of guidelines which are not designed to address the ethical issues relevant for social scientists. He also emphasised the importance of separating legal compliance from ethical reflexivity and ethical compliance. Although these are linked, they are not the same.

He raised the concern that many researchers choose not to see ethical issues and ethical dimensions in their work; if they choose not to see them, they do not have to deal with them. Therefore, there is a need for training in order to help researchers, above all, to embrace and therefore recognise, understand, and identify ethical issues. Making this a success requires establishing and reinforcing the ethical structures that will support the research community at the 'host institution' level.

A successful implementation would lead to researchers not regarding ethics as a bureaucratic hurdle, but rather as an important component of research that adds quality to their work. It is a question of having better, rather than more, ethics supporting the design and impact of well-conducted research.

Mr Karatzas offered a number of examples of challenging ethical issues where special attention and care are required, for example when working with vulnerable subjects such as children or illegal immigrants, or doing research where deception of participants or others is required to either obtain useful research results or to protect the researcher and/or participants. Researchers often face difficulties in justifying this research to an ethical review board, especially if the board is inclined to be risk-averse.

There is also the challenge of obtaining informed written consent. Informed written consent from participants is recognised as the 'gold standard'. However, there are many scenarios where individuals may require anonymity (for example, those living in 'grey' administrative areas or beyond the radar of standard social monitoring), making this impossible. Under these circumstances, what is a realistic alternative to informed written consent, and who is equipped to define such solutions?

These scenarios highlight the need for social sciences and humanities scientists who are also qualified in ethics to be more active in contributing to standard ethical review boards. Often these have been established according to biomedical models, with social scientists being outnumbered by natural scientists. Increased participation of social sciences experts and the added presence of their expertise in biomedical ethical boards, or even the establishment of social sciences-focused ethical committees, could improve guidance and advice in complex situations through a deeper understanding of the specific research questions which are often debated in social sciences theoretical frameworks.

Consent and Cybermetric Data

In her case study on the SuperIdentity project, **Professor Sarah Stevenage** from the Faculty of Social and Human Sciences at Southampton University, UK, further explored the issue of informed consent.

The SuperIdentity project is a multidisciplinary approach to examining the nature of modern identity, and how it exists as a combination of online and offline elements. The project created a dataset to investigate the reliability of individual identity cues and the linkage between them. There was clear academic value in data sharing, and having already gained the informed consent of the participants, the project had originally intended to make the dataset public. However, in the time after initially obtaining the consent, advances in technology increased the risk of re-identification. For this reason the project team took the decision, as part of a duty of care to the research participants, not to release the data. This was despite having ethical approval, and ran contrary to the formal expectations of the funders.

This case study posed a number of questions about the nature of written informed consent, particularly as it relates to cybermetric data. Participants can only give their informed consent to risks that the researchers make them aware of, which are the ones known to the researchers at the time of requesting consent. However, is this consent permanent, or should changes in technology and the possible emergence of new risks require consideration of dynamic consent models? In addition, how does consent apply in the secondary use of data, where there is a risk of 'function creep' (that is, using data for a purpose other than that for which it was originally collected)? Ethical protocols – and funder expectations – need to consider these issues. These are questions that will need the input of social sciences and humanities, and that biomedical research alone cannot address.

Issues of informed consent and dynamic informed consent require renewed consideration, while issues of data sharing and data management require new approaches or legal frameworks. Most of all, however, researchers require training to improve understanding of these issues, and to reach fundamental agreement on key principles.

Similar questions are emerging from several research fields due to the rapid advances in technology. Therefore a new ethical framework may need to be more inclusive, bringing issues emerging from a wide variety of research areas under a single umbrella, with an understanding of diverse research interests.

Challenges of Streamlining Processes

Dr Marie-Sophie Peyre, Scientific Adviser, Ethical Issues, European Research Council Executive Agency (ERC), used the issue of vulnerable groups to further highlight the need for streamlined ethical approval processes. As an example, she set out a number of scenarios where written consent could pose a threat to the safety of research participants. Individuals in vulnerable situations – such as refugees, non-documented migrants or those living in war zones – may be willing to participate in research but equally may have valid concerns over protecting their identity. Institutions hosting ERC grants may seek the highest ethical standards, but often they lack the capacity to help researchers resolve these issues in ways that still allow them to conduct their research.

Once again, the scenario highlights a lack of both capacity and of expertise. If ethics are to become embedded in social sciences, then the relevant expertise has to be developed and resourced.

Managing Ethical Risks

Professor David Martin, Deputy Director of the Administrative Data Research Centre for England (ADRC-E), examined attitudes to data handling of administrative data, and outlined a potential model for managing ethical risks in ways that address public concerns.

An IPSOS-Mori poll on behalf of the UK Economic and Social Research Council (ESRC) found that the public held few objections over the use of administrative data for research purposes, subject to certain important caveats.⁵ There should be strong governance, effective de-identification and de-linkage, and a clear public – not commercial – benefit to using the data. The ADRC network model helps to address these issues.

This model recognises three critical levels of scrutiny: of researchers, of project aims, and of the role of the ADRC itself. In this regard, ADRC will accredit researchers. Then, when an accredited researcher requests access to data, a panel will evaluate whether or not the proposed project will deliver a clear public benefit, is drawn on data that is essential to their research and is not available elsewhere.

Once a request is approved, the ADRC assemble the requested data sets, taking responsibility for linkage and de-identification. Importantly, in the language of data protection the ADRC acts only as a 'data processor', not as a 'data controller'.

This approach accommodates public concerns, and creates a 'sweet spot' between researchers, the nature of data supplied and where the data are located. The model has proved financially sustainable following significant start-up funding.

Moving Forward

Two breakout sessions addressed (1) issues of governance and (2) principles of best practice. The sessions focused on identifying ethical tensions between current guidelines and emerging research needs, and on how to increase awareness of these tensions in order to mitigate them. The breakout sessions showed the added value of the social sciences community, with participants examining their own research and framing a coherent set of practices that define ethical standards not yet addressed in previous guidelines.

It was clear from the discussion that the social science community needs to take ownership of those ethical approaches that shape its work and that best frame the results of its investigations. Social scientists are best placed to recognise the specific challenges for their disciplines and understand how to deal with them. Their ultimate goal will be to ensure that researchers have an appropriate ethical 'reflex'. This allows them to envisage the ethical implications of their work at the design stage. At the same time, the social science community needs to establish authority for its ethical approach, principles and guidelines through a common voice. The benefits will be threefold: providing a solid framework for researchers, reassuring the wider public, and better managing the expectations of funders.

Nevertheless, academic institutions and funders need to continue to tackle the lack of appropriate infrastructures, such as social sciences-focused ethical boards, as well as the increasing pressure on the existing social sciences-focused boards from other disciplines, which find biomedical ethical committees still inadequate to assess the ethical issues of their research questions.

Recommendations

In the final session, the participants of the workshop formulated a number of recommendations and identified future actions for researchers and research institutions, as well as for policy makers who address the need for a more robust and effective ethical framework for today's research. Participants agreed that current guidelines have addressed important aspects of research subjects' safety but they are not exhaustive. Recent research bringing together social scientists, biomedical researchers and clinicians, for example, has highlighted several areas where collaboration is greater than the sum of its parts. Ethical guidelines are part of the same kind of multidisciplinary collaboration.

The participants agreed the following set of recommendations:

▶ Provide reassurance to the public on the ethical dimensions of data use

There is a growing public awareness of the ethical dimensions of data use, with significant implications for social sciences. The public recognises the potential of data sharing and its impact on privacy.

The social science community needs to reassure the public that they will handle their data safely, sensitively and appropriately.

▶ Take ownership of ethics in social sciences

By creating high standards for ethics within social sciences, collaboration with other disciplines would inevitably improve. Given the direction of travel towards multidisciplinary projects, this would enhance the role of social sciences. It would also ensure that a lack of appropriate ethical frameworks does not subject social science research to inappropriate substitutes.

Social science researchers need to take the lead in defining ethical standards in their disciplines and determining their own core ethical principles.

▶ **Speak with a single voice – create a ‘Declaration of Helsinki’ for social sciences**

The group highlighted a number of considerations that need to be taken into account when initiating such a declaration. Although there are many lessons to be learned from pioneers in ethics, such as biomedicine, any declaration must not be a simple transposition of ethical approaches from other disciplines. Instead, it needs to be a bespoke fit, if it is to meet the specific demands of social science. It also requires training researchers to understand these issues and create fundamental agreement on key principles.

The social science community needs to be seen to speak with a single voice on the issue of ethics. A clear statement of principles would provide a strong statement of intent. The community also needs to design appropriate training for researchers.

▶ **Ensure that any declaration has realistic parameters**

The principles need to be high-level, rather than prescriptive, whilst remaining grounded in reality. At the same time, they need to retain sufficient flexibility, to accommodate the increasing frequency with which social science researchers co-operate with other disciplines.

Any declaration needs to have realistic parameters and enough flexibility to meet a wider range of discipline-specific demands.

▶ **Develop ethical expertise**

On a practical level, the group recognised that there was a lack of ethical expertise to train those researchers with responsibility for ethical review. Building sufficient capacity will require time and investment. There will also be a need to overcome a built-in resistance to change; many researchers may view ethics as a barrier, rather than an aid, to quality research.

The social sciences community and research funders need to develop expertise at national and international level.

▶ **Flexibility in ethics committees**

The participants recognised that there are benefits in having ethics committees with flexible participation. Ethics panels need to be made of those experts who can best address the ethical issues that the research questions and methods raise in a given proposal, rather than being predetermined.

Ethics committees need to be flexible and allow the adequate participation of experts with appropriate knowledge to address the ethical issues of the proposed research.

▶ **Ensure that ethical considerations are applied appropriately**

Processes should be robust but should also take account of the differing levels of risk that each individual project may pose. They should reflect the real ethical issues and challenges of the specific research questions addressed in the proposal.

New approaches to ethical guidelines need to address a wider variety of disciplines and research practices, rather than impose a single model.

Possible Follow-up Activities

The workshop highlighted a range of specificities and needs within social sciences that inform and enrich the debate on ethical standards. The Science Europe Scientific Committee for Social Sciences aims to continue working to raise awareness of these issues through the following actions:

- ▶ Contributing to reviewing the current 'state of the art' in ethical protocols in research. The objective is to ensure that the social sciences research perspective is included in any future set of guidelines, and to gather a more active community of researchers who share similar standards.
- ▶ Using the discussion at the workshop as an opportunity to stimulate a deeper dialogue with funders on ethical requirements. The aim is to promote a greater dialogue between researchers and funders on ethical expectations, in order to manage expectations and improve clarity for all from the outset.
- ▶ Raising awareness about the lack of social sciences competencies in existing ethical committees and promote the setting up of ethical boards with a broader set of disciplinary skills at the institutional level.
- ▶ Using the current recommendations and conclusions to inform further debate. This will include input into discussions at a workshop planned by the ERC in November 2015 on ethical procedures in research funding, and an ongoing review of the UNESCO recommendation on the status of scientific researchers.



Thursday 11 June 2015 // Thon Hotel, Brussels

10.30–10.40 Welcome and Introduction
Professor T. Risse, Chair of the Science Europe Scientific Committee for the Social Sciences
Dr G. Lombardo, Science Europe

10.40–10.50 Introduction by the Organisers
Professor J. Falkingham, Southampton University, UK

10.50–11.50 Tour de Table: Questions and Discussions

Presentations

12.00–12.25 Eight Lessons Learned from Eight Years of Ethics Reviews of EU-funded Projects
Mr I. Karatzas, DG Research, European Commission

12.25–12.50 Case Study on the Superidentity Project
Dr S. Stevenage, Southampton University, UK

13.50–14.15 The Coming Birth of a Streamlined Ethics Process in Social Sciences Research
Dr M.-S. Peyre, European Research Council Executive Agency

14.15–14.40 Administrative Data Research Network – A Service for Researchers: a Solution to Manage Ethical Risks
Professor D. Martin, Administrative Data Research Centre for England, UK

Break-out Sessions

14.40–15.40 **Session 1: Roles and Responsibilities – Fit for Purpose?**
 Facilitator: **Professor J. Falkingham**, Southampton University, UK

Session 2: Recommendations Towards Good Practice as a Route to Determining Principles for Future Endorsement
 Facilitator: **Dr E. Whitley**, London School of Economics, UK

16.00–17.00 Conclusions and Next Steps

Organising Committee

Jane Falkingham, Gabi Lombardo, Sarah Stevenage, and Edgar Whitley

For further information, please contact

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1. <http://www.wma.net/en/30publications/10policies/b3/index.html>
2. M. Israel, (2014) Research Ethics and Integrity for Social Scientists. Beyond Regulatory Compliance (Sage), pp.18-19
3. http://ec.europa.eu/justice/data-protection/files/factsheets/factsheet_data_protection_en.pdf
4. See also N. Whiteman (2012) Undoing Ethics: Rethinking Practices in Online Research (Springer), pp.9-10
5. <https://www.ipsos-mori.com/Assets/Docs/Polls/pas-2014-main-report.pdf>



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