

# Ethics and Legal Challenges of SSH Research\*

## Background and Description

Research ethics and the legislative regime(s) within which social sciences and humanities research takes place have long been the concern of researchers within the SSH domain. Technological advances giving rise to new methods of data collection and data creation amplify the ethics issues which need to be addressed and extend the requirements for researchers in relation to legal provisions.

Allied with these technological changes, cross-national research raises particular ethical and legal challenges to which researchers have to respond and researchers' codes of practice may not have been developed apace.

Deliverable 6.1 gives a broad overview of the *various legal and ethical challenges* researchers in the SSH domains currently are confronted with and provides a general discussion of the *legal, institutional/administrative and ethical frameworks* in relation to SSH research.

Besides core ethics principles for scientific research, such as

- respect for autonomy,
- beneficence,
- non-maleficence and
- justice,

which govern ethical considerations of researchers conducting research involving human subjects, the report identifies data protection law and copyright law as those sets of legal provisions that are particularly relevant for the conduct of research.

## Challenges

The focus of the report lies on issues which currently concern the SSH ESFRI research infrastructures (CESSDA, CLARIN, DARIAH, ESS, SHARE) in their day-to-day operations of SSH data collection, data processing and data sharing. In line with these different stages of the research process *general challenges* related to the following topics are identified:

- Obtaining informed consent
- Anonymisation and pseudonymisation
- Data access and usage restrictions

These general issues entail certain *specific challenges* connected to different types of data and/or different ways of SSH data collection, such as:

- The collection of dried blood spots in the context of population-based surveys
- The collection and harvesting of language data
- The linking of micro-level administrative record data to survey data
- Technology-based language data collections
- The use and release of paradata
- The access to and re-use of previously published (copyrighted) language data

These specific challenges are closely connected to certain SSH research project and require project-related practical solutions. Challenges related to general ethics issues and legal requirements as well as issues related to the legal and administrative frameworks, on the other hand, are of common interest across different SSH disciplines and projects.

\* DASISH WP6 Deliverable 6.1: Schmidutz, D., Ryan, L., Gjesdal, A., De Smedt, K. (2013). Report about New IPR Challenges: Identifying Ethics and Legal Challenges of SSH Research. Available at: <http://dasish.eu/deliverables/>.

## Findings and Conclusions

In the report the following general legal and ethical issues, in particular with regard to the ethical, legal and administrative frameworks in Europe, can be identified that are of particular relevance with regard to present and future research in the SSH domains:

- The on-going controversial discussions and negotiations about the provisions of the proposed new **European General Data Protection Regulation** cause uncertainties regarding the implications of the Regulation with regard to research data generation and management in the SSH domains and the extent to which the Regulation will affect the work of existing data archives and SSH research infrastructures. Certainly some of the recently proposed amendments would have serious negative consequences for SSH research (and in particular for register based research) if being transposed into EU legislation.
- Since the European Data Protection Directive (95/46/EC), which currently regulates the protection of individuals with regard to the processing of personal data within the European Union, has failed to achieve proper harmonisation of data protection laws across the European countries, currently the **fragmentation of data protection law in the EU Member States** poses a big challenge to cross-country SSH research.
- The **organisation of the national ethics committee systems in Europe** differs a lot between the different EU Member States, and the same applies for the approval procedures. When conducting transnational or transregional research projects that require approval of various national/regional ethics committees (e.g. cross-disciplinary research including the collection of biological samples), identifying all committees responsible and applying to them in accordance with the respective national or regional policies and procedures may pose serious problems and even may prevent research.
- **Technological developments** and in particular the Internet not only open doors to new and enriching possibilities in research but also pose a challenge to researchers, since they amplify ethical challenges and give rise to specific issues which are not covered in existing ethics codes.

With regard to future legal challenges, obviously the most significant issue raised at present relates to the **European Data Protection Reform** – since the provisions of the forthcoming European General Data Protection Regulation will provide the legal framework for future research in the SSH domains.

On the whole, for scientific research in all SSH fields and particularly for register based research, including linking survey data with administrative record data, the amendments that have been made – which suggest removing many important research provisions/derogations granting research a privileged position with regard to data access and the use of personal data – are devastating.

Due to the possible negative consequences for SSH research, which the anticipated General Data Protection Directive may have, from an SSH perspective, the further development of the proposed Regulation and its possible effects concerning the collection, processing and dissemination of different types of data occurring in the SSH domains should be closely observed.

Furthermore, since the European institutions are currently entering a crucial stage in the legislative process, whenever possible the opportunity should be taken to call the attention of research funding institutions and ministries (among others) to the damaging effects that the proposed amendments will have on research and society when being implemented.

### Further Reading

Schmidutz et al. (2013). Report about New IPR Challenges: Identifying Ethics and Legal Challenges of SSH Research. Available at: <http://dasish.eu/deliverables/>

