Data Protection and Ethics Committees in Social Science Research

David Erdos
Centre for Socio-Legal Studies, University of Oxford
david.erdos@csls.ox.ac.uk
http://www.csls.ox.ac.uk/dataprotection
Overview

1. (Briefly) summarize data protection (in EU-15)
2. Explicate restrictions it can impose on research in social science
3. Examine the same vis-à-vis research ‘ethics’ committees
4. Contrast situation with ‘journalism, literature and art’
5. Brief conclusions

N.B. This is an ongoing study of a complex issue. Exact provisions are stated to the very best of my ability but may be subject to amendment.
What is Data Protection (DP)

**EU-wide legal framework** which regulates the “processing” of

Encompasses **anything** done electronically (e.g. even reference on an unstructured web page (Lindqvist (2003))) of “personal information”

According to EU = **any** information about identifiable individual (e.g. author and a book title, Who’s Who info.) with origins from 1960s onwards & aims to prevent information “miscuse”
DP Principles

1. Fair and Lawful Processing *
2. Limited, specified and compatible purposes
3. Relevant (adequate and not excessive)
4. Time limited
5. Accurate (and where relevant up-to-date)
6. Subject’ Rights Adherence
7. Secure
8. No export without “adequate protection”

• These broad principles are filled out or specified by detailed rules.
DP rules (out of principles):

- “Fair & lawful”
- Registration with DPA
- Legitimating Condition for Processing
- Fair Obtaining of Data
- Data Subject Notification
- (Presumption) ban on sensitive data processing

• But whole framework also limited by **purpose specific special provision**.
DP Exemptions:

- **Extensive and (strictly) compulsory** special provision for **journalism, literature and art**.

**Article 9 (Directive)** - Member States must provide such exemptions from all but the security principle if this is necessary to reconcile the right of privacy with the freedom of expression.

- By contrast only a series of **sporadic and highly specific** exemptions for **“history, statistics and research”**.
- These are therefore subject to most of the provisions of the **general scheme**.
Data Subject Notification

- Article 10 of Directive sets out duties:
  - Requires data subject to be provided with:
    - the **identity** of the controller (& representative),
    - the **purposes** of the processing,
    - **other information** to make processing fair.

- Provides no exemption when direct data collection (including photographs & audio)
- 4/15 national laws do provide for limitations (& Portugal provides for possibility of DPA license)
- But even here may make **covert and/or deceptive research “almost certainly” illegal** (Jay, 2004).
Data Export: Adequate Protection

- General ban on export of data outside EEA absent “adequate protection” (Article 25.1) or consent
- No research exemption from this in any EU-15 country.
- According to Working Party 29 includes publication on internet (as well as manual transfer & email)
- Threat to research sharing and even apparently worldwide publication of personal data:

“Data may not be collected from, or transferred to countries outside the EEA unless that country has adequate data protection regulations, or the explicit consent of the data subject has been obtained, or there is an appropriate contract with the recipient of the data, specifying the data protection requirements that must be upheld. In most cases, the only safe option will be to ensure that participants give explicit consent for overseas transfer during data collection.” (ESRC, Framework for Research Ethics, 2010)
Sensitive Data Regime

Any information revealing:
• racial/ethnic origin  • political opinion  • religion or philosophical beliefs  • trade union membership  • health  • sex  • crime

• Starting point is that such processing is banned
• Exemptions possible if substantial public interest and safeguards

Greece – Exceptional circumstances plus “provides that anonymity is maintained and all necessary measures for the protection of the persons involved are taken”

UK – (i) substantial public interest; (ii) does not support measures/decisions; (iii) does not cause substantial harm or distress.
Prior Authorization

- Many countries combined safeguards set out in law with requirement for DPA authorization

Applies re: sensitive data in Austria, Denmark, Belgium, France, Greece, Portugal and Sweden

- May be other authorization requirements (e.g. further processing, data export, non-notification for indirect data collection).

- Effectively operates as a potentially highly arbitrary form of a prior restraint.

- In Sweden, however, may be waived by research ethics committee approval (“self-regulation”)
Social Science ‘Ethical Review’

- Rise of system of pre-emptive institutional regulation of social science since early 2000s

  Documented bans re:
  - participant observation
  - ‘informal’ or ‘verbal’ consent
  - non-anonymous reporting of results

  Documented requirements for:
  - Parent consent for all under-18s
  - Absolute right to retract data

- Cogent critique against what is seen as a system of arbitrary, risk-averse censorship (e.g. Dingwall, 2006; Hammersley, 2010)

- But system shows signs of continuing to expand....
Conclusion – a way forward?

- Must **defend & sell** core mission of producing **important knowledge** for the **public benefit**.

**Journalism, literature & art purposes covers all activities which have as their object “the disclosure of information, opinions or ideas....They are not limited to media undertakings” (European Court of Justice in *Satamedia* (2008))**

- Need to demand that **Universities**, the **legislature** and the **regulator** provide us with the protections offered to others.
- Given the **pan-EU review** of the framework now underway there is no better time to act.