Towards an international electronic repository and virtual laboratory of open data and open-source software for telehealth research

Comparison of international, Australian and Finnish privacy policies

Personal Data

Record/Register Research
careful consideration & compliance with the appropriate governance, policy, & legal frameworks
International Policies

- Individuals basic right to privacy
- Declaration of Helsinki on Ethical Principles for Medical Research Involving Human Subjects
- Data privacy protection laws in Sweden
- Belmont Report for the Protection of Human Subjects of Biomedical and Behavioral Research
- Lisbon Declaration of the Rights of the Patient
- OECD Es + transborder movement
- EU Es
- APCE Es
- EU proposal (globalisation, new ICT)

Policies in Australia and Finland

- Nurnberg Code on for Human Experimentation
- Declaration of Helsinki on Ethical Principles for Medical Research Involving Human Subjects
- Initialising the project
- Initial discussions, research plan, research group, group leader
- Developing the ethical protocol:
  1. Studying the governance, policy, and legal frameworks.
  2. Furnishing the proper permissions and following the legislation.
  3. Monitoring that the permissions cover all aspects of project.
  4. Specifying the purposes of data collection (relevance, amount).
  5. Specifying data collection, storage and protection: data access, destruction, use, modification, and disclosure.
  6. Preparing user agreements.
  7. Educating the data users on research ethics.
  8. Answering to questions on research ethics.
  9. Monitoring that good research practice is confirmed.
  10. Intervening in problems.

Law

- Commonwealth of Australia
- Higher national authority
- Regional differences:
- Examples:
- European Union (EU member since 1995)
- Ministry of Social Affairs and Health
- No
- The EU directive supplemented by:
  - Act on Electronic Perceptions (E 2007).
  - Act on Personal Data (152 1999).
  - Act on the National Data Inspectorate for Health Care (945 1989).
- Act on the Notti and Rights of Patients (620 1999).
- Act of Raising Health or Social care data information (159 2007).
- Clinical Code of Fraud on 11888.
- Decree of Ministry of Social Affairs and Health about Patient Records (201 2001).
- 746 2010.
- Personal Data Act 158 1999
(www.datainspector.dk)
Process of Getting Data: B

Ethics approvals & research permissions
1. The study is accepted by chief officers of the jurisdiction.
2. Ethics approvals are obtained from the approving authority.
3. Research permissions are obtained from the jurisdictions (and in some cases from the highest national health-authority).

Ethics Approvals

Needed for any health information acquisition or work with patients beyond routine care
Except for register studies without connections to invasive studies in Finland

Authority: National Health/Medical Research Ethics Committee + site-specific sub-committees
Standardised forms: NEAF/TUKJA forms
Review times: monthly/fortnightly meetings
Review costs: 0 - 5,000 AUD, depending on commercial sponsorships

Informed Consent

From the patient (and healthcare worker in Australia)

Some exceptions (e.g., inability due to the amount of data)

Research Permissions in Finland
How to perform international studies?
Transborder Aspects

Australia: the transferrer remains accountable unless:
1. the recipient is subject to a law, binding scheme or contract which effectively upholds adequate privacy protections,
2. data subjects have been consented for the transfer or
3. authorisation by or under another law.

Finland: transfer is possible only if 1, 2, or 3 holds.

Process of Getting Data

Q: What happens to data and derived resources?
A: Typically returned to the jurisdiction or deleted

Keynotes:
A/Prof Pierre Zweigenbaum, LIMSI-CNRS and ERTIM-INALCO, France
Prof Jon Patrick, University of Sydney and Health Language Laboratories, Australia

Summer School: 4-8.2  Workshop: 11-12.2  NICTA Techfest: 13.2