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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

Hanna Suominen
Senior Researcher
PhD, MSc

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Health Information

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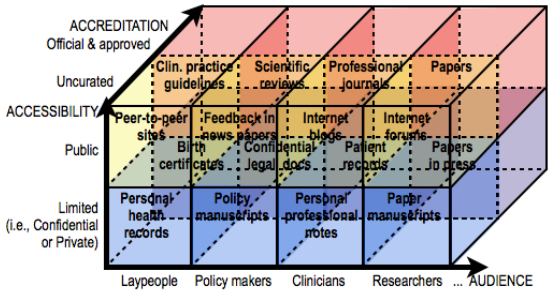

Personal Data

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Record/Register Research

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careful consideration & compliance
with the appropriate
governance, policy, & legal frameworks

International Policies

'50 1940 Individuals' basic right to privacy
Nurnberg Code on for Human Experimentation
'60
'70 Declaration of Helsinki on Ethical Principles for Medical Research Involving Human Subjects
1st eData privacy protection laws in Sweden
European equivalents (Es)
'80 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
'90
2000 EU Es
'10 APEC Es
EU proposal (globalisation, new ICT)

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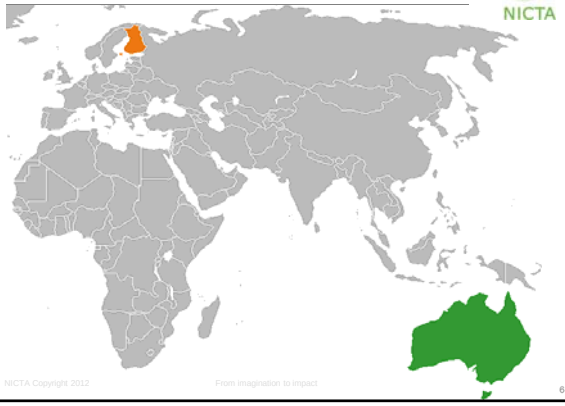
Policies in Australia and Finland



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Process of Getting Data: A

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 conformed.
10. Intervening in problems.

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Law

Harmoniser	Commonwealth of Australia	European Union (EU, member since 1995)
Highest national authority	Dep. of Health and Ageing, National Health and Medical Research Council	Ministry of Social Affairs and Health
Regional differences	Yes, for states/territories	No
Examples	Australia: Privacy Act (www.privacy.gov.au/law/act) New South Wales (NSW, www.legislation.nsw.gov.au): - Health Records and Information Privacy Act 2002 (NSW), - NSW Health Privacy Manual, Version 2, 2005, - NSW Health Electronic Information Security Policy, Version 1, 2005, - NHMRC National Statement on Ethical Conduct in Human Research, 2007, and - Privacy and Personal Information Protection Act 1998 (NSW).	The EU directive[13] supplemented by - Act on Electronic Prescriptions 61/2007, - Act on Private Health Care 152/1990, - Act on the National Personal Data Registers for Health Care 556/1989, - Act on the Status and Rights of Patients 785/1992, - Act of Reading Health or Social care client information 159/2007, - Criminal Code of Finland 39/1889, 940/2008, - Decree of Ministry of Social Affairs and Health about Patient Records 298/2009, - Health Care Law 1326/2010, - Law on Medical Research 488/1999, 794/2010, and - Personal Data Act 523/1999 (www.finlex.fi).

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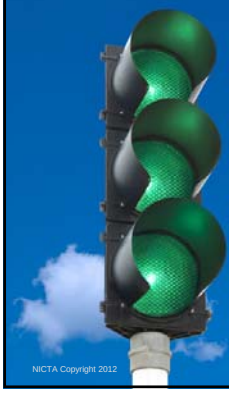
Process of Getting Data: B



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).

From imagination to impact

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/TUKIJA forms

Review times: monthly/fortnightly meetings

Review costs: 0 - 5,000 AUD, depending on commercial sponsorships

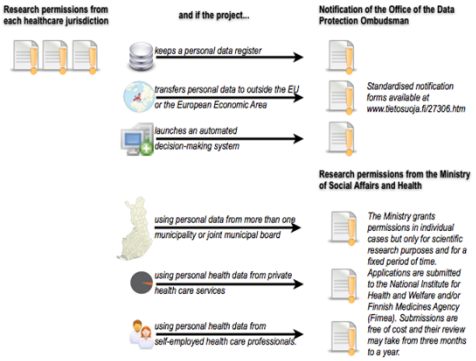
Informed Consent

From the patient
(and healthcare worker in Australia)

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

From imagination to impact

Research Permissions in Finland

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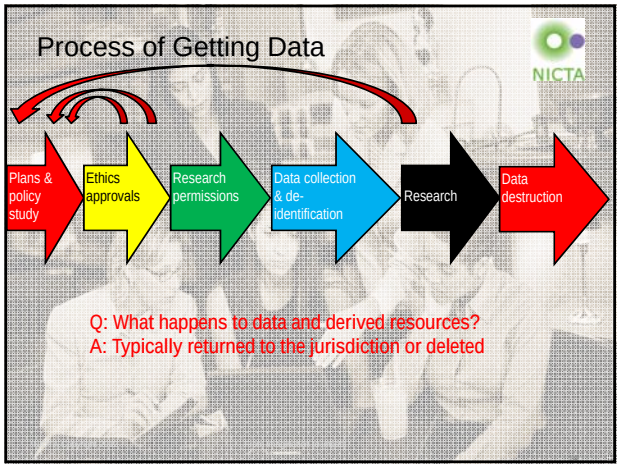
How to perform international studies?
Transborder Aspects
Australia: the transferrer remains accountable unless:
1. the recipient is subject to a law, binding scheme or contract which effectively upholds adequate privacy protections,
2. data subjects have been consented for the transfer or
3. authorisation by or under another law.
Finland: transfer is possible only if 1, 2, or 3 holds.


Process of Getting Data
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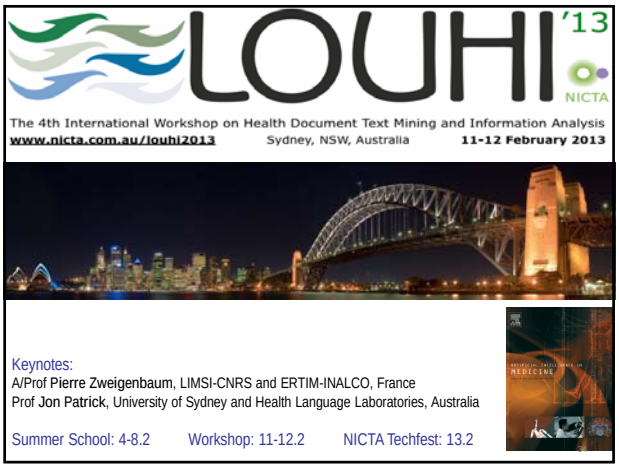
Plans & policy study
Ethics approvals
Research permissions
Data collection & de-identification
Research
Data destruction
Q: What happens to data and derived resources?
A: Typically returned to the jurisdiction or deleted


LOUHI '13
NICTA
The 4th International Workshop on Health Document Text Mining and Information Analysis
www.nicta.com.au/louhi2013
Sydney, NSW, Australia
11-12 February 2013
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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