

NCRIS

National Research
Infrastructure for Australia

An Australian Government Initiative



BIG DATA, DATA LINKAGE & ETHICS

Presented by Felicity Flack

- ❖ Data Landmarks – the data environment
 - ❖ Navigating the data world for researchers
-

The Data Tsunami



Definition

Open means anyone can freely access, use, modify and share for any purpose.

Open Data



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TECHNOLOGY BLOG

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Blog home

Government data: full text of David Cameron's letter pledging to open up the datasets

The prime minister has launched a week of open data with a public letter calling for government departments to open up the datasets. Here is the full text

Posted by Simon Rogers Tuesday 1 June 2010 23:23 BST guardian.co.uk Comments (6)

Article history

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Next

scientific policy - Peer review and scientific publishing

*“Information collected by or for the public sector is a national resource which should be managed for public purposes. That means that we should reverse the current presumption that it is secret unless there are good reasons for release and presume instead that it should be freely available for anyone to use and transform unless there are compelling **privacy, confidentiality or security** considerations which require otherwise.”*

Australian Government 2.0 Taskforce, 2009.

Privacy and Confidentiality



Privacy

The right of people to control their personal information

Confidentiality

The treatment of information disclosed in a relationship of trust e.g. doctor/patient

Personal information

information or an opinion, whether true or not, and whether recorded in a material form or not, about an identified individual, or an individual who is reasonably identifiable

Privacy and Confidentiality

❖ Statute authorising collection, use and disclosure

No breach where comply with statute

❖ Duty of confidentiality

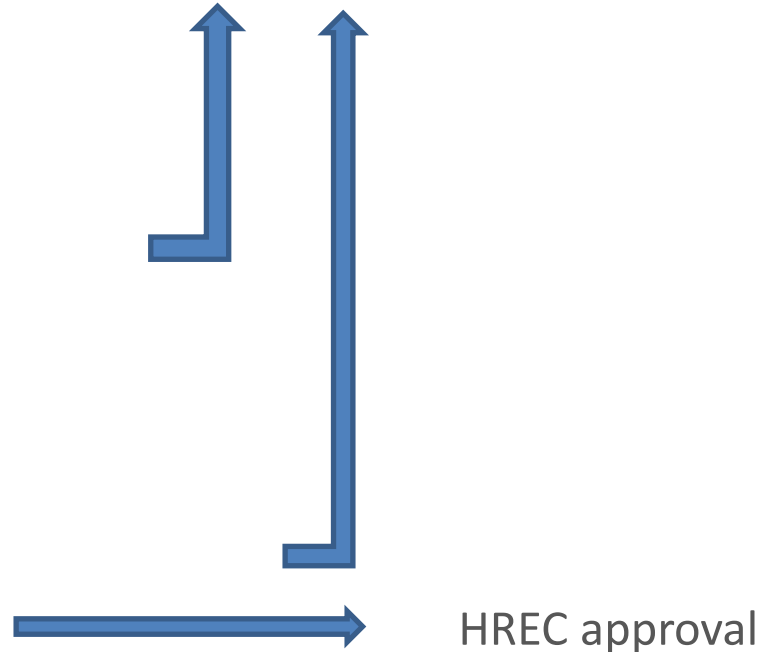
No breach where:

- Consent
- Statutory authority

❖ Privacy legislation

No breach where:

- Consent
- Statutory authority
- Research exception



Research Ethics



United Nations International Covenant on Civil and Political Rights

Article 17

1. No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation.
 2. Everyone has the right to the protection of the law against such interference or attacks.
-

United Nations International Covenant on Economic, Social and Cultural Rights

Article 15

1. The States Parties to the present Covenant recognize the right of everyone:
 - (a) To take part in cultural life;
 - (b) To enjoy the benefits of scientific progress and its applications;**
 - (c) To benefit from the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author.
-

PART 2: Navigating the Data World



PHRN
Population
Health
Research
Network



Core Ethical Values

- ❖ Research Merit and Integrity
 - ❖ Justice
 - ❖ Beneficence
 - ❖ Respect
-

“Bad science = bad ethics”

- ❖ Data quality
 - ❖ Skills and experience
-

- ❖ That there is fair distribution of the burden of participation
 - ❖ That there is fair distribution of the risks and benefits of the research
-

- ❖ 86% of Australian households have access to the internet
- ❖ 99% of 15-17 year olds are internet users
- ❖ 51% of people aged over 65 are internet users
- ❖ 93% of employed people use the internet
- ❖ 70% of unemployed people use the internet

“The likely benefit of the research must justify the risk of harm or discomfort to the participants”.

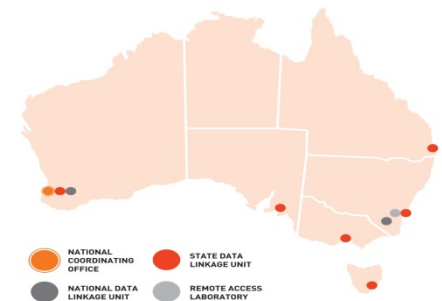
The most common risk is the breach of privacy

❖ Things that increase the risks:

- Type of information
 - Quantity of information
 - The information held by the person that receives it
 - The skills and technology of the person that receives it
-

- ❖ Infrastructure to mitigate privacy risks include:
 - Systematic data linkage
 - Secure transfer
 - Secure access facilities e.g. SURE

<http://www.phrn.org.au/>



Recognition of the value of human autonomy – including the capacity to make one’s own decisions including decisions about personal information

If no consent then how to demonstrate respect?

- ❖ Put yourself in the participants shoes
 - ❖ Mitigate privacy risks
 - ❖ Community involvement in research
 - ❖ Publication and dissemination of results
 - ❖ Translation of research findings
-

How to survive the tsunami



- ❖ Be prepared
 - Get your legislation in order
 - Rethink the National Statement with respect to data
 - Minimise duplication of ethical review
- ❖ Seek higher ground

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Thank you

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