

Human research ethics, privacy and emerging technologies

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Privacy – why does it matter?

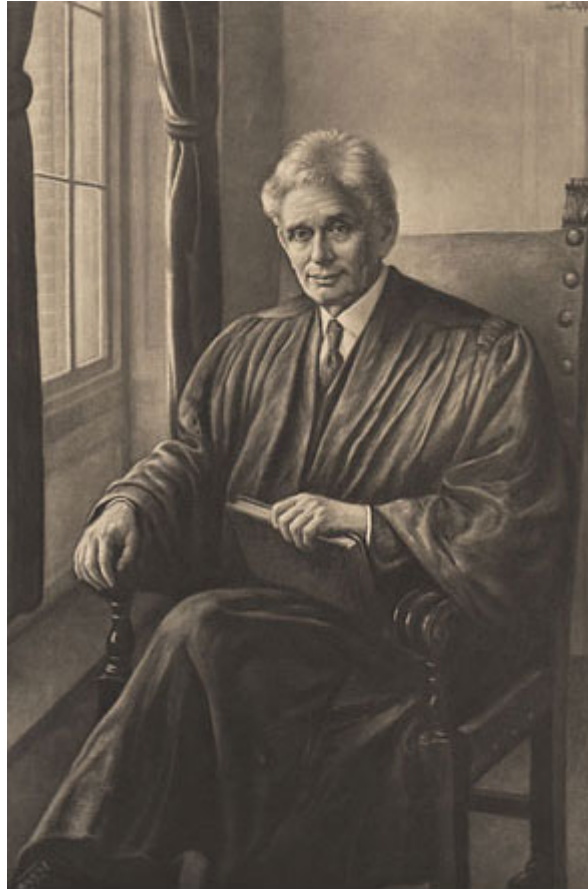
- **Privacy is a basic human right**
- **It's the law**
- **It's fundamental to the conduct of human research –**

Society has granted a conditional privilege to perform research on human beings... [T]he condition is that it must be conducted in a way that puts the rights and welfare of human subjects first.

-- US Guidelines for the Conduct of Research Involving Human Subjects at the National Institutes of Health , 2004



‘...the right to be let alone’



Portrait of Louis D. Brandeis by painter Joseph Tepper.
Photoengraving on paper, 1939, Harvard Law School Library.



Human Right



Privacy is...

Privacy has several dimensions –

- Privacy of the body
- Privacy of the home
- Freedom from surveillance
- Freedom from communications monitoring
- **Information privacy**



The privacy protection landscape

Information privacy laws

Cth Privacy Act

- Federal & ACT govt agencies & much of the private sector

Vic Info Privacy Act

- **Victorian state & local government organisations**

NSW, NT, Tas, Qld privacy laws

SA privacy standards

Health privacy laws

Cth Privacy Act

- Health info held by federal government agencies and private sector bodies

Vic Health Records Act

- Health info and health service providers in Victorian public & private sectors

ACT, NSW health privacy laws

Other legal & ethical obligations

Cth data-matching and TFN laws

FOI & archives laws

Surveillance laws

Spent convictions laws

Human rights charters

Duties of confidence

NHMRC National Statement

Collection

- Notice
- Sensitive information
- Unique identifiers

Use and disclosure

- Primary purpose
- Related purpose person would reasonably expect
- Consent
- Public interest (including research)
- Transborder data flows
- Unique identifiers



The IPA and research

- Unlike the Cth Privacy Act & Vic Health Records Act:
 - There are no binding, statutory guidelines applying to researchers
 - No express obligation for ethics review and monitoring
 - The Victorian Privacy Commissioner has no power to issue Public Interest Determinations or guidelines that depart from IPPs
- The IPA leaves intact existing obligations to comply with National Statement when conducting research funded by (or carried out under the auspices of) NHMRC, ARC or AVCC



Research in the public interest (without consent)

- IPP 10.2: Collection of sensitive information allowed for research or statistical analysis relevant to government funded targeted welfare or educational services, where impracticable to seek consent
- IPP 2.2(c): use or disclosure allowed where necessary for research, or compilation or analysis of statistics, where:
 - the research is in the **public interest**; and
 - it is **impracticable** to seek the individual's prior consent; and
 - the organisation providing data to the researcher reasonably believes that **the researcher will not disclose** the information further; and
 - any particular individual will **not be identified in any publication**.

Data quality

Make sure personal information is:

- accurate
- complete
- up-to-date

Data security

- Take reasonable steps to protect personal information from misuse, loss, unauthorised access, modification or disclosure.
- Personal information should be destroyed or de-identified when it is no longer needed.



Consent

- Consent is foundational in human research
- Elements: capacity; voluntary; informed; specific; current
- Capacity to waive or dispense with consent:
 - Waiver of consent under the National Statement
 - “Impracticability” of seeking consent under the IPP 2.2(c)(i) & 10.2(c)
- But consent usually needed to collect sensitive information

The cloud



The cloud II

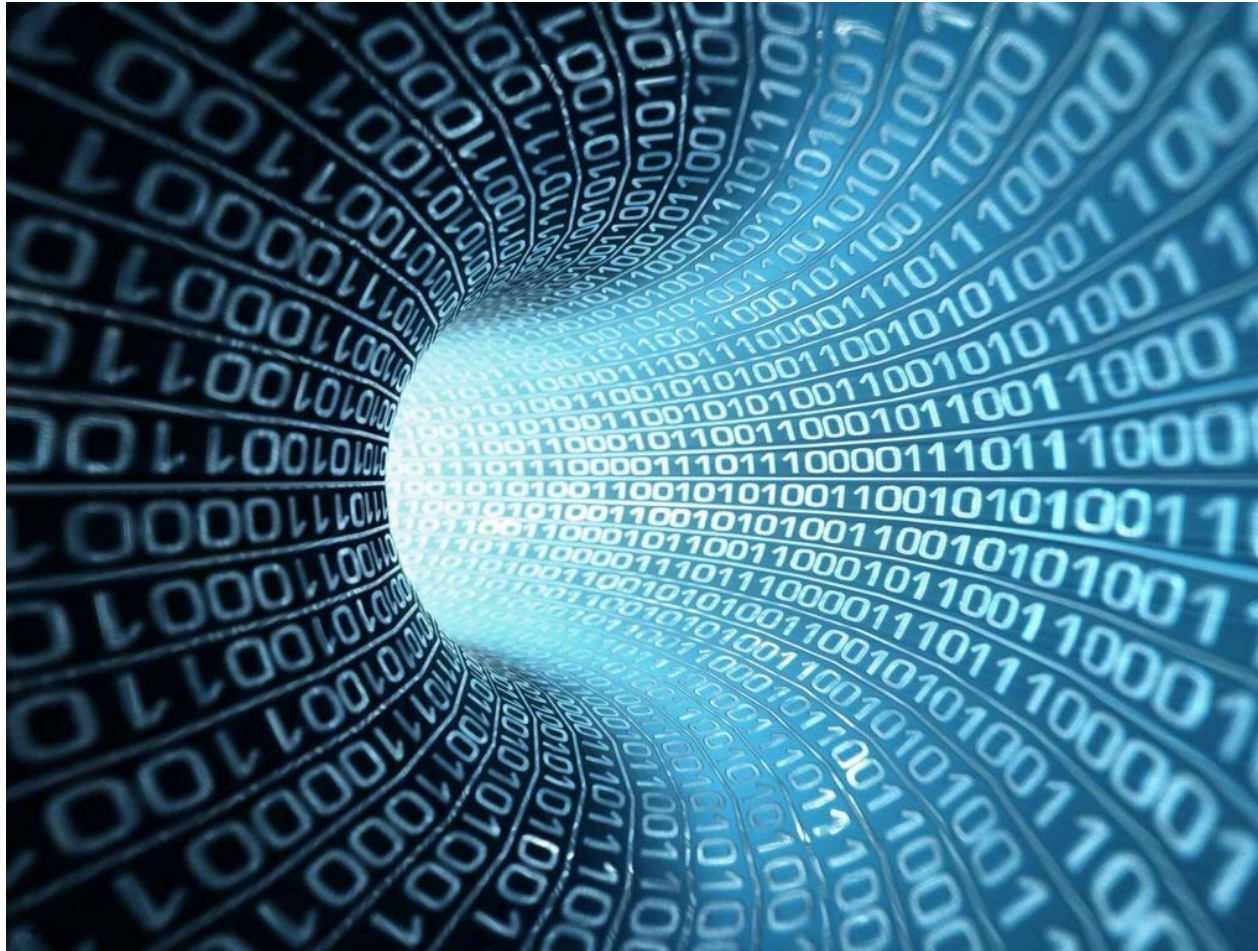
- Potential privacy implications:
 - Collection & notice
 - data security
 - transborder flows
- Loss of control
- Accountability

Social media

- Anonymity/pseudonymity
- Notice
- Consent
- Public spaces or private rooms?
- Role of researchers – observers or participants?
- Control – security, access, retention, disposal



Big Data



Big Data II

- De-identification?
- Notice, choice and consent - now redundant?
- “Right to be forgotten” – how would this work in a world of big data?
- Is national sovereignty still meaningful?
- Is regulation even possible?



More information

Privacy Victoria

www.privacy.vic.gov.au

1300 666 444

Federal Privacy Commissioner

www.privacy.gov.au

1300 363 992

Victorian Health Services Commissioner

www.health.vic.gov.au/hsc

1800 136 066

