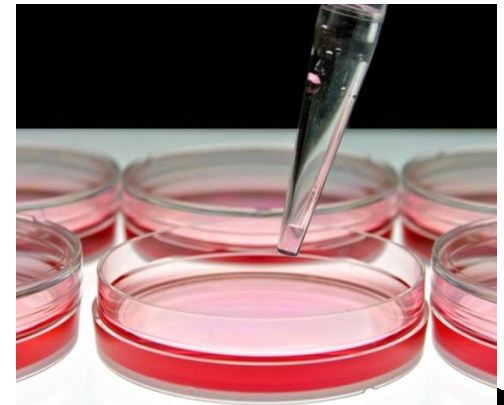


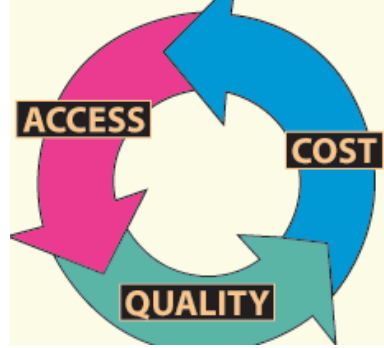
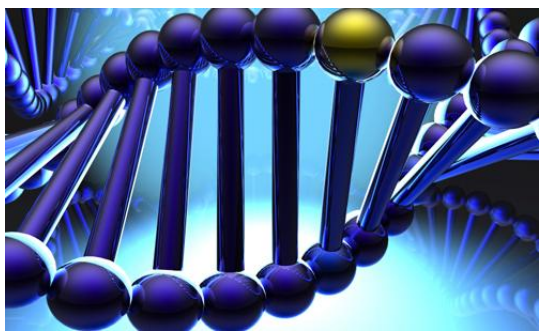


Malcolm Crompton

Sensitive health information and privacy

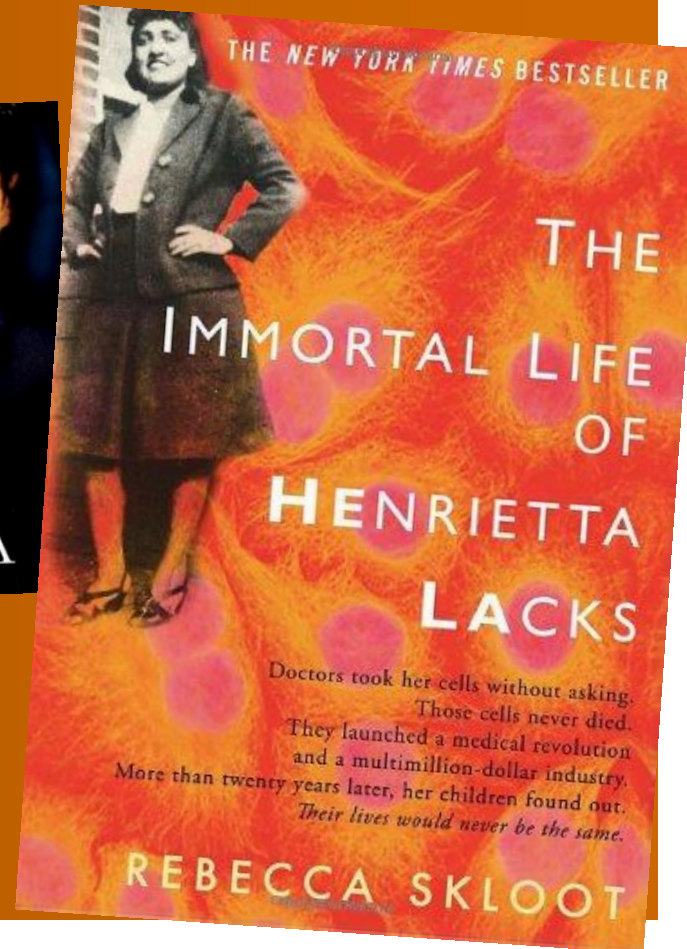
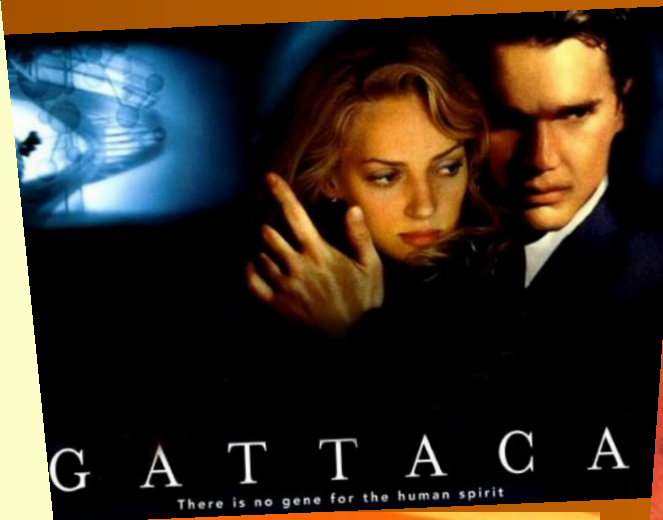
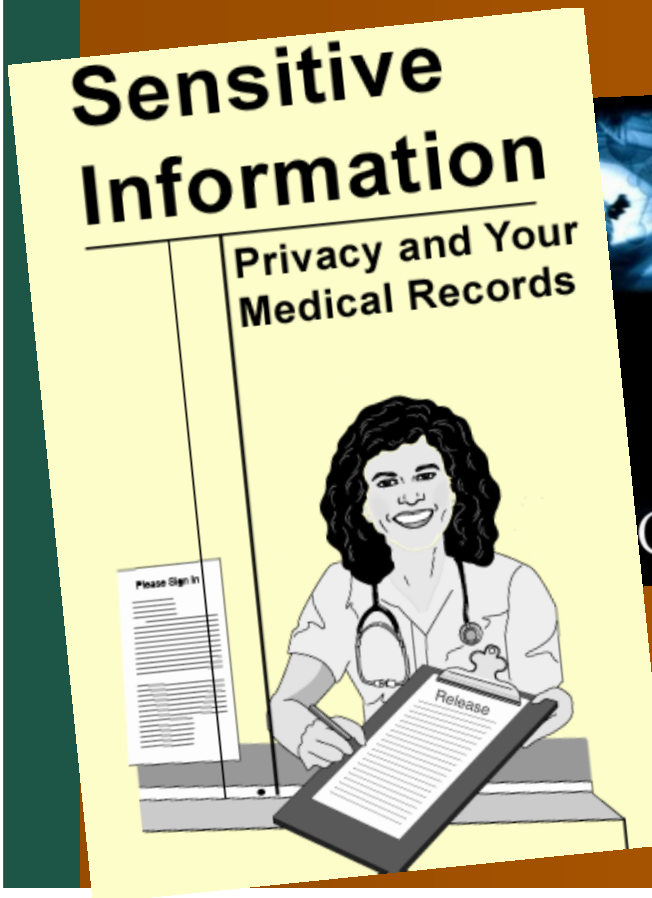
Canberra
30 August 2011





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There is no gene for the human spirit

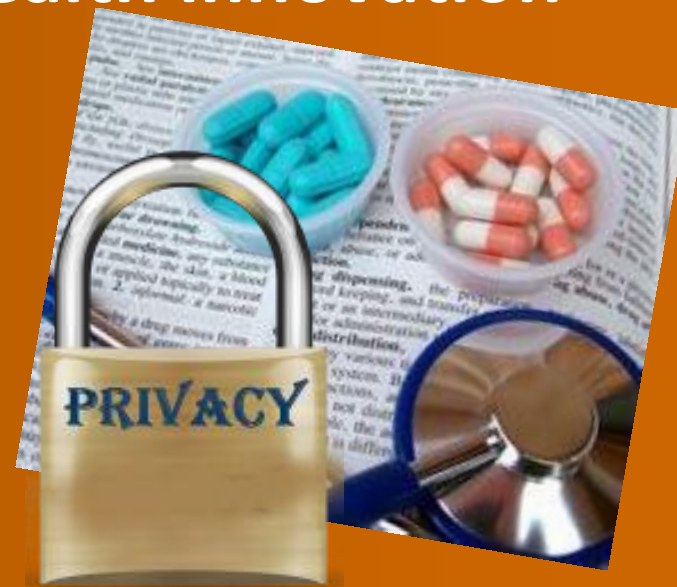




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“Privacy requirements stifle health innovation”

- legislation prevents us from gathering and mining data, limiting the information we have for trials
- health consumers don't understand the work we do, so they won't voluntarily consent to us accessing their health information
- complying with privacy requirements costs money that could be better used for health research and development

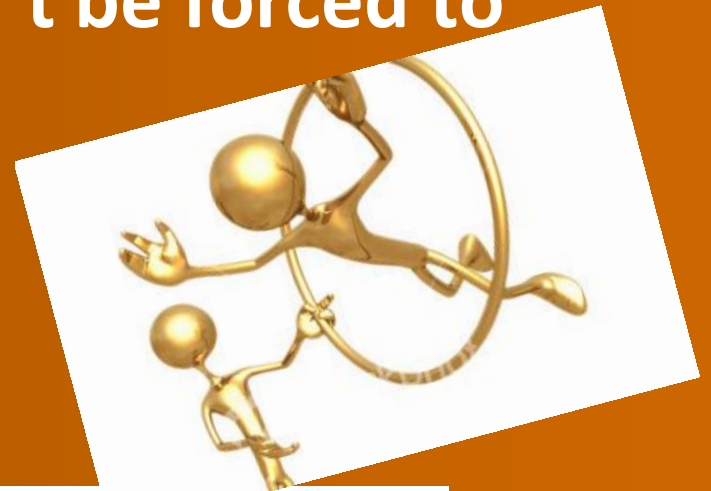


**EXPECT
DELAYS**



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Health research is so important for the community that we shouldn't be forced to jump through privacy hoops



THE Public
Interest

Guidelines Under Section 95
of the Privacy Act 1988

Guidelines approved under Section 95A
of the *Privacy Act 1988*

Use and disclosure of
genetic information to a patient's
genetic relatives under Section 95AA
of the *Privacy Act 1988* (Cth)

Guidelines for health practitioners in the private sector
Issued by NHMRC on 27 October 2009

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Some health privacy “hoops”

- *Privacy Act 1988*
 - s95 - Medical research guidelines (government agencies)
 - s95A - Guidelines for National Privacy Principles about health information (private sector)
 - s95AA - Guidelines for National Privacy Principles about genetic information (private sector)
 - National Privacy Principle 10 - Sensitive information (private sector)
- National Health and Medical Research Council (NHMRC) Statement on Ethical Conduct in Human Research (government agencies and private sector)



National Statement on Ethical
Conduct in Human Research

Developed jointly by
National Health and Medical Research Council
Australian Research Council
Australian Vice-Chancellors' Committee

medicare

PBS



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And more hoops

- Medicare and Pharmaceutical Benefits schemes (MBS and PBS) – data from the two schemes must be stored separately
 - Australian Privacy Commissioner Privacy Guidelines for the Medicare Benefits and Pharmaceutical Benefits Programs
- Armed forces and veterans – in return for receiving health care, defence personnel consent to collection of their health information
- Life Saving Drugs Program (LSDP) *“Financial assistance will only be provided where the patient agrees to participate in the evaluation of efficacy of the treatment by periodic medical assessment as directed.”*



Community concern is real ...

- Ponemon Institute *Benchmark Study on Patient Privacy and Data Security* (Nov 10)
 - \$12 billion – cost of data breaches for hospitals in the USA
- Ponemon Institute *Americans' Opinions about Healthcare Privacy* (Feb 10)
 - >73% of respondents do **not** trust the federal government to protect the privacy of their health records
 - 71% **do** trust healthcare providers to protect the privacy of their health records
- Australian Privacy *Commissioner Community Attitudes to Privacy 2007*
 - 76% believe that if a National Health Information Network existed, inclusion in it should be voluntary

Accountability and Privacy-By-Design Go together Like Innovation and Productivity

www.informationpolicycentre.com http://www.privacybydesign.ca/content/uploads/2010/03/PbD_Abrams_Nov09.pdf

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And there is a way ahead: the emerging framework

- Tools we can build in to our work
 - Layered Defence
- How to build in the tools
 - Privacy by Design
- How to know the tools are being applied year in, year out
 - The Accountability Project



The logo for the Centre for Health Record Linkage (CHRL) features the letters 'CHRL' in a large, bold, white font. Below the letters, the full name 'Centre for Health Record Linkage' is written in a smaller, white font. The logo is set against a dark purple background with a subtle circular pattern.

Centre for Health Record Linkage

The logo for CURF MicroDATA is displayed in a white, bold, sans-serif font on a blue background. To the right of the text is a graphic of a microchip with a keyhole, symbolizing data security and access.A graphic showing a close-up of a document with the word 'communication' in a large, bold, serif font. Other words like 'ate with', 'sage commu', and 'something that' are partially visible above and below the main word.The logo for Information Integrity Solutions features the words 'INFORMATION', 'INTEGRITY', and 'SOLUTIONS' stacked vertically in a white, bold, sans-serif font. The text is set against a dark green background with a vertical orange stripe on the left side.

Getting it right

- now more ways to use data that doesn't identify people
 - restricted/altered data, statistical disclosure control, remote analysis servers
 - WA Data Linkage System, NSW & ACT Centre for Health Record Linkage (CheReL), ABS Confidentialised Unit Record Files (CURFs), CSIRO Privacy-Preserving Analytics
- consent as an opportunity to gain community trust
 - take the public into our confidence & the public can have confidence in us
 - transparency & communication
- if consent not possible, stronger governance & accountability
 - NHMRC – Australian Health Ethics Committee (AHEC), Research Committees



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Going beyond the minimum

- Medical research is possible with
 - better statistical methods & infrastructure
 - transparency & demonstrable good governance
- But Henrietta Lacks must never happen again



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Malcolm Crompton

Managing Director

53 Balfour Street

Chippendale NSW 2008

Australia

+61 407 014 450

MCrompton@iispartners.com

www.iispartners.com