

Health Privacy Futures 2008

Realising the Opportunity

Brisbane - 10th and 11th November - Royal on the Park

INFORMATION
INTEGRITY
SOLUTIONS

Malcolm Crompton

*Health information exchange:
Is there only one road ahead?
Or many?*

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We know we have a changing “terrain”

- Review of the *Privacy Act 1988*

www.alrc.gov.au/inquiries/current/privacy/index.htm



- The internet has changed the rules



- Demand for health care has changed





New models of health care essential

- Prevention
- Patient centric approaches
- Integrated care – multi-disciplinary teams
- Self help
- Care in the community
- New technology seen as key enabler



Key ingredients

The knowledge enterprise

- Networked information
- Support for autonomy and personalisation
- Systems that are open, adaptive and distributed

Connectivity

- “Connecting power” the key, not monolithic solutions
- Once connected individual value propositions will drive standards and agreements

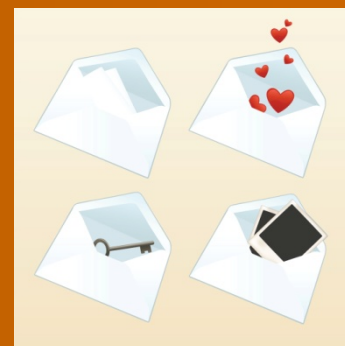
Open networks

- Design to accommodate the heterogeneity and incompleteness of information, the distributed information sources and users, and the various forms of institutions part of health care.



Mix of privacy attitudes in the community

- Some don't care – want to share – “just fix me”
- Some can't care – dementia, mental disability, medical emergency
- Some very private – “you will only know what I want you to know, even if it means I don't get the best care.”
 - eg see [California Healthcare Foundation](#)



Mix of contexts with different drivers and information needs



- Clinical treatment
 - User control, if wanted, most important and possible here
- Health research
 - Need access to whole of population data – need special processes – transparency and accountability important here
- Broad health policy
 - Transparency and de-identification needed here

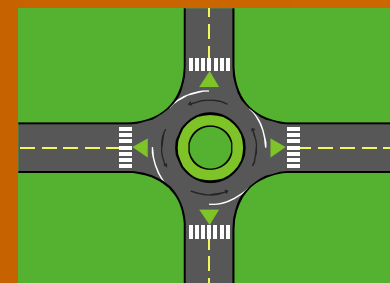




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Is it just one road? – the privacy implications

- Major implications for personal information
- Environment heterogeneous
- Users heterogeneous
- No magic bullet solution
- May need UHI to bring common strands together
- BUT – need creative thinking to find the right approach to respect for health information, particularly with regard to any UHI



A one size fits all approach won't work

- Not good enough to cater just to those who don't care at all
- Not good enough to cater just to those who want extreme privacy
- Not good enough to cater just for what the health provider thinks the health consumer wants





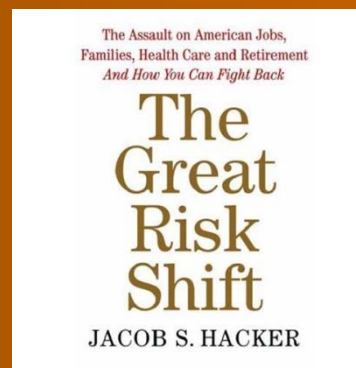
Layered defence

- Technology – barriers where needed
- Business processes – consumer control where possible, MOUs, Service Agreements,
- Transparency – but must be easy to access and in context
- Accountability – to demonstrate you are doing what you said you would
 - Enhancement but not function creep
- Good customer support and external review when system fails



Don't place entire burden on notice and consent:

- Notice obligations = avalanche of notices \neq more privacy
- Shifts risk to individuals
- Front end loading
- Single control point
 - maps poorly to multi-use networked health information

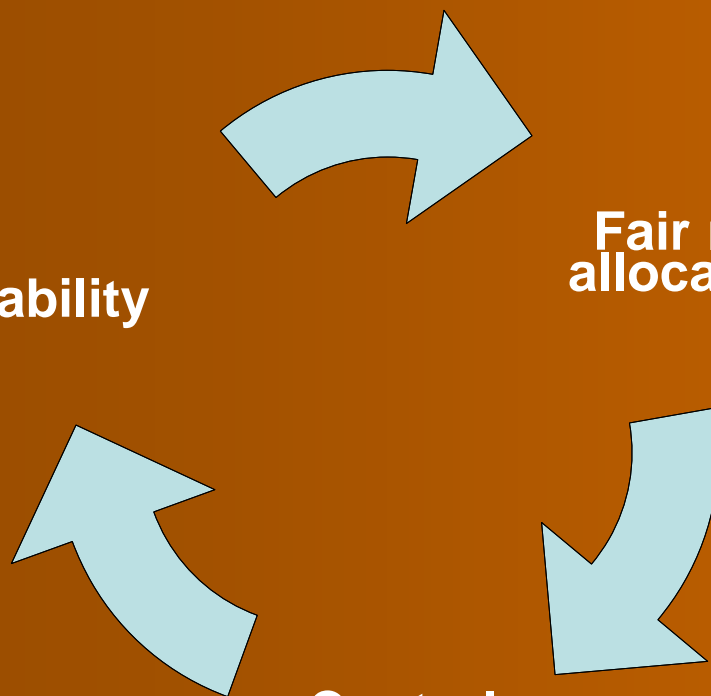


Three key dynamically related elements

Accountability

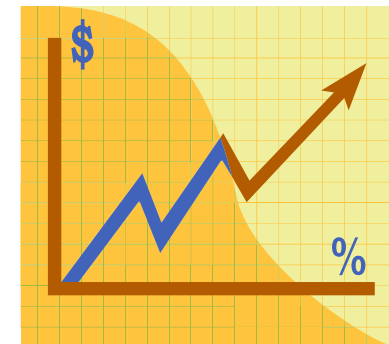
Fair risk
allocation

Control



Good identity management maybe the key privacy issue

- A Unique Health Identifier may be necessary
- BUT:
 - Identifier should be just that – carry no additional pay load
 - Pseudonymous or anonymous where possible
 - Health consumer choice where possible – able to opt in and opt out
 - Strong measures to prevent it becoming a national identifier – no hidden agenda



Which turn will we take?

- Many forks in the road ahead not a bad thing
- Will require clever combination of trial and error/flexibility and standardising
- Emphasis on health consumer perspective as much as other interest
- No monopoly on approach
- Incentive is extremely important



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