

A fresh look at “balancing” Patient Privacy & Clinical Safety

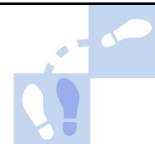
*Managing Patient Confidentiality and
Information Governance*

22 August 2011, Melbourne

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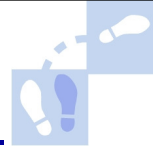


A fresh look at privacy



- Privacy = *control* not secrecy
- Important legal precedent
- The case for Health IDs
- How many identities do we need?
- The future of identification and privacy

Privacy is ...



- Not about security
- Not all about secrecy
 - “Public” & “Private” not important
 - “Ownership” is not important
- Is about control
- Is akin to consumer protection
- Is about respect
 - *Use limitation, openness etc.*

The balance metaphor



Privacy



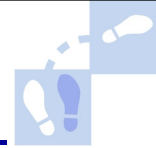
**Safety
Efficacy
Medico-legal certainty**



**We have a saying in this business:
*Privacy and security
are a zero-sum game***

**Ed Giorgio, Office of the Director of National Intelligence,
New Yorker, 21 Jan 2008**

KJ v Wentworth Area HS



- Oncology patient under care of multi-disciplined team
- Psychiatrist shared case notes amongst team



Disclosure



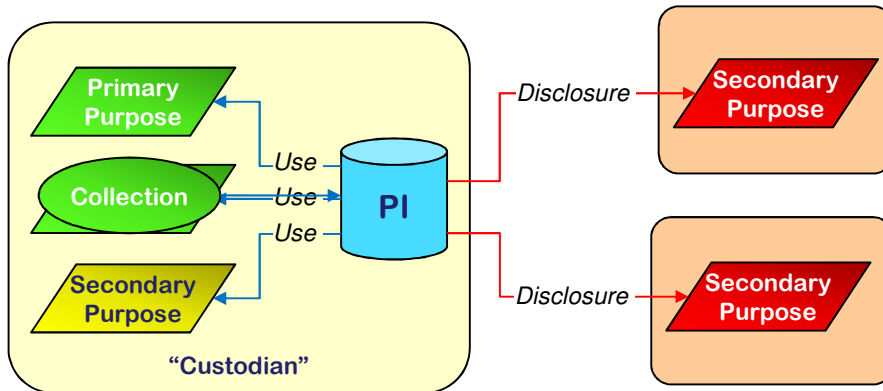
NPP 2.1 An organisation must not use or disclose personal information about an individual for a secondary purpose ... unless:

(i) the secondary purpose is related to the primary purpose of collection and, if the personal information is sensitive information, directly related to the primary purpose of collection; [and]

(ii) the individual would reasonably expect the organisation to use or disclose the information for the secondary purpose; or

the individual has consented to the use or disclosure ...

Use vs. Disclosure



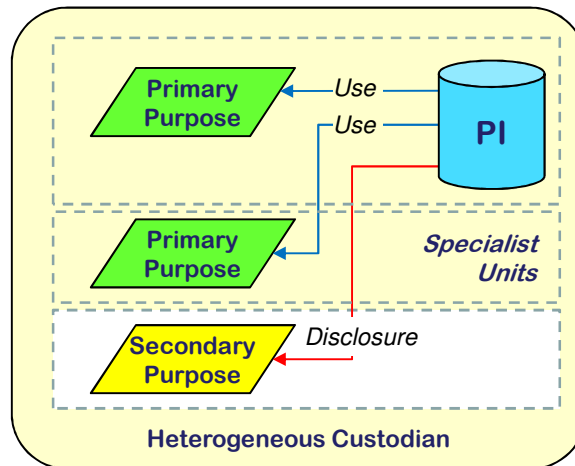
Disclosure: generally requires notice be given, before or after the fact
Disclosure of **Sensitive Information:** generally requires prior **consent**

Precedent

KJ v Wentworth Area Health Service (2004):

While generally speaking the expression "disclosure" refers to making personal information available to people outside an agency, in the case of large public sector agencies consisting of specialised units, the exchange of personal information between units may constitute disclosure.

Use vs. Disclosure



KJ v WAHS upshots

- **Privacy Notices revised (widely)**
- **Healthcare exemptions to Privacy interpreted more narrowly than clinicians might expect**
- **Be conservative about patient expectations**
- **Don't let clinical orthodoxy trump all**

Digital Identity today



Facebook's Zuckerberg: "Having two identities for yourself is an example of a lack of integrity"

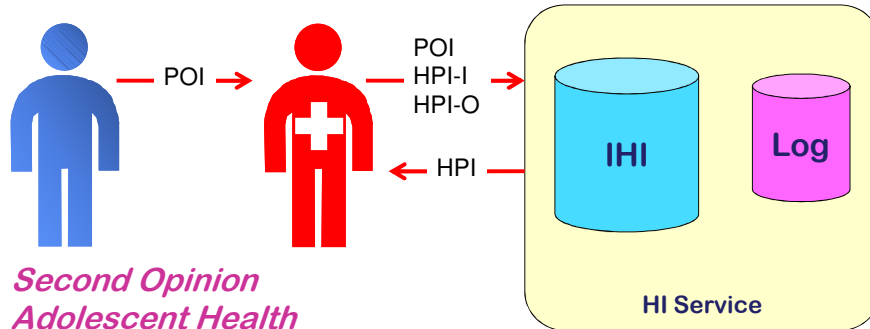
<http://michaelzimmer.org/2010/05/14/facebooks-zuckerberg-having-two-identities-for-yourself-is-an-example-of-a-lack-of-integrity>

How many identities?



- **Deeply entrenched views**
 - #realnames
 - #nymwars
- **Lesson: *Intuitions may be flawed!***

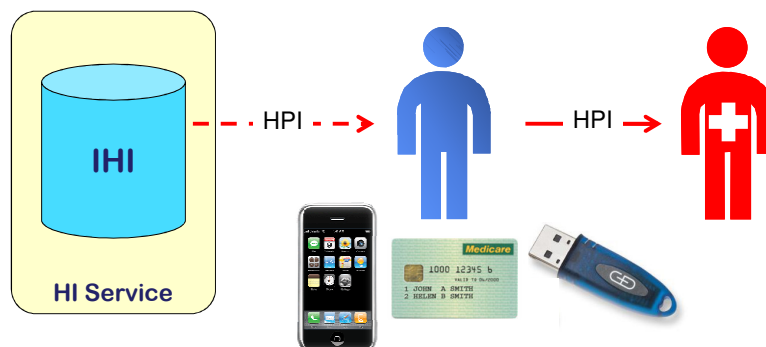
Centralised IHI architecture



*Second Opinion
Adolescent Health
Family Planning
Small town problems
Abortion
Drug & Alcohol*

Q: How is the IHI case impacted if patients lose faith?

A decentralised IHI



**Need to Know principle
More choices
More scaleable**

How many identities?



- IHI
- Local URNs
- Medical Social Networking
- Clinical Trials
- Given the choice ...
 - Mental health
 - Sexual health
 - Drug & Alcohol

The future of identity



- Better outcomes from better participation
- EHRs' public health benefits
- Patients will opt-in to trusted systems



Further reading



- *The Trouble With “Balance” Metaphors*
www.juliansanchez.com/2011/02/04/the-trouble-with-balance-metaphors
- *Patient Privacy and Security - Not a zero sum game!* Wilson et al, Australian Epidemiologist V12.1, 2005
http://lockstep.com.au/library/ehealth/patient_privacy_and_security
- *“I’ve Got Nothing to Hide” and Other Misunderstandings of Privacy* (paper) Daniel Solove <http://bit.ly/obxnvA>
- *Nothing to Hide: The False Tradeoff Between Privacy and Security* (book), Daniel Solove
<http://docs.law.gwu.edu/facweb/dsolove/Nothing-to-Hide/index.html>
- *KJ v Wentworth Area Health Service* New South Wales Administrative Decisions Tribunal [2004] NSWADT 84
http://www.ipc.nsw.gov.au/lawlink/privacynsw/ll_pnsw.nsf/pages/PNSW_07_cnadt84

Discussion



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