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eHealth



SHAPING THE FUTURE OF HEALTHCARE

Health Privacy Futures - The Road Ahead

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The Road Ahead ...

- Sounds like the beginning of a story ... rather than the end
- In the NEHTA context this can signify a number of options; today I'll cover a few possibilities
- Some practical, some aspirational
- Along the way, I'll outline NEHTA's approach to privacy, with illustrations drawn from NEHTA's work program



Privacy, policy and legal issues

- Not surprisingly, the NEHTA work program throws up a number of privacy, policy and legal issues
- These are often intertwined or interdependent
- NEHTA has a role in identifying, analysing and resolving policy and privacy issues (either internally or externally)
- A number of consultative mechanisms are also used to obtain feedback “beyond NEHTA” (internal and external)



Privacy

- Privacy - the quintessential “wicked problem”?
- A recent publication cited the following descriptions of privacy: “a concept in disarray”, “exasperatingly vague and evanescent”, “the Cheshire cat”, “chaos”, “infected with pernicious ambiguities” ...
- ALRC Review of privacy - three volume final report and almost 2700 pages
- Feedback to NEHTA reflects the complexity of views and demonstrates the difficulty of accommodating (sometimes divergent) views



NEHTA's approach to privacy

- *NEHTA's Approach to Privacy* (July 2006)
- NEHTA's Privacy Management Framework - structured and flexible - applied to relevant NEHTA initiatives
 - Initial application identifiers and shareable e-health records (commenced 2006)
 - Expanded to "packages" in late 2007 (i.e. pathology, discharge, referral and medications management)
 - Includes privacy blueprint process, roundtables, public consultations and PIAs
- Next? *NEHTA's Privacy Management Framework* (early 2009)



What have we learnt?

- It is important to start at the beginning ... (privacy over consent)
- A structured, repeatable Privacy Management Framework enables a flexible, responsive and disciplined approach to privacy
- Importance of “the narrative” for all stakeholders
- Privacy input must occur from the beginning; “embedding” process is necessary (technology; project teams; privacy services)



Current situation

- There is widespread recognition of the key health issues facing Australia:
 - A “tsunami” of chronic disease
 - An ageing population
 - Workforce, workforce, workforce
 - A growing gap between advantaged and disadvantaged health consumers
 - An increasing number of new and expensive health technologies
- E-health is an enabler for key areas of health reform; good privacy management supports e-health



Summary

- It's rarely about the technology (although it can produce better and worse privacy outcomes)
- It's always about change management, culture, the business proposition (where is the "killer app" in e-health?)
- Privacy functions as a floating threshold and is "hinge-like" (it can be a force for good and evil)
- There is a need for more positive, practical examples of privacy being incorporated successfully into e-health



What I would like to see (nationally)

- A solution to the privacy patchwork
- E-health “foundations” in place (secure messaging, identifiers, clinical information/terminologies, authentication)
- A growing number of successful national e-health solutions (discharge summaries?) that, in turn, provide a strong foundation for a future IEHR platform
- A growing number of Australian privacy professionals



What I would like to see (NEHTA)

- Publication of *NEHTA's Privacy Management Framework*
- Ongoing development of the framework in partnership with public and private sector organisations
- Privacy knowledge distributed through the organisation - we practice on ourselves!
- Evidence through implementation that good privacy practice is an enabler for e-health



Questions?

Book reference:

Understanding Privacy, Daniel J. Solove (Harvard UP: 2008)
pp.1-2

