

# Using Personal Health Information: Do We Manage Conflicting Interests?

# Privacy legislation

Protects personal information unless and until:

- The information is deemed not personally identifiable
- An instrumentality that is exempt from the privacy legislation requires the information
- A matter of public interest is deemed more significant than individual privacy
- The law is changed

# Changing the law

- 2006: the NSW government changed the NSW Privacy Regulation to allow its electronic health record system to operate as an opt-out rather than an opt-in model
- 2009: the Commonwealth government changed the *Australian Health Insurance (Compliance) Bill* to allow Medicare to access personal health records as part of its audit processes

# Contributing to the discussion

- Do individual health informatics professionals have the responsibility for considering the possible implications of the systems we create?

OR

- Should that discussion be the responsibility of our representatives in the peak bodies, so we can get on with making sure the systems we create do what they are expected to do?

# Codes of ethics/professional conduct

- IMIA:
  - health informatics professionals ‘have a duty to ensure, to the best of their ability, that appropriate structures are in place to evaluate the technical, legal and ethical acceptability of data use in the settings in which they carry out their work or with which they are affiliated’ (2012)
- ACHI:
  - the health informatics professional should respect the rights and interests of others (2012)

# The study

- Analysis of health informatics literature
- Not from the peak bodies
- HISA conference papers: the voice of the community
- A discourse analysis

# Discourses

- Technology discourse
  - a major goal in a modern health care system is to represent the state of a patient's health and the health of a community in a way that is useful for automatic processing by computers
- Clinical discourse
  - the driving force of those systems were clinicians and the main purpose was to support clinical practice

# Discourses

| Discourse                      | Scope, focus, issues  |
|--------------------------------|---|
| Scholarly discourse            | Discussed health informatics in terms of academic issues. The discourse emphasised effective resolution of health information management issues as best achieved through the accumulation of a formal body of knowledge to inform the practice of appropriately accredited health informatics professionals |
| Management discourse           | Discussed information and information management systems as supporting good management practices  |
| Health technology discourse    | Represented the discipline as primarily concerned with identifying and resolving the technical problems associated with the construction and implementation of clinical computer/information systems  |
| Clinical informatics discourse | Focused on the activities of clinicians in the immediate clinical environment   |
| Nursing discourse              | Spoke of health informatics in terms information management for nursing, practice   |
| Populations discourse          | Populations discourse was concerned with issues around the collection and use of aggregated data and information for service planning and implementation to proactively improve and maintain healthy population   |

# Can we/should we

| Discourse                      | Basis for support for expanded use of personal health information  |
|--------------------------------|--|
| Scholarly discourse            | Acknowledged the need to protect privacy, while arguing strongly for access to personal information for research purposes  |
| Management discourse           | Pursuit of management goals was a legitimate reason for changing the privacy/public interest balance. Discussions focused on consumer privacy; use of personal information to monitor staff was justified in terms of achieving the organisation goals |
| Health technology discourse    | Secure technical systems were represented as the key to meeting privacy requirements while maximising approved access to personal information and discussions focused on technical solutions to facilitate rather than restrict access to information  |
| Clinical informatics discourse | Located privacy issues within the context of clinical care where professional practice and codes of ethical behaviour prioritise privacy and confidentiality   |
| Nursing discourse              | Located privacy issues within the context of clinical care where   |
| Populations discourse          | Argued for expanded access to both de-identified data and personal health information for public health research and policy development  |

# Function creep

- When personal information is used
  - for purposes not specified when the information was collected
  - in ways not clearly related to the original use of the information
  - or used without the consent of the person to whom the information relates

# Function creep

- 1993: The information on the INCIDE database does not identify individual patients, is not used to pinpoint individual clinicians or facilities
- 2006: The clinical reporting repository contains a suite of reports which allow Heads of Units to analyse the performance of their own unit and compare the relative performance of units within hospitals
- 2009: The system provides a means of monitoring the assessment skills and care delivery of each practitioner as well as giving an effective method of review

# Function creep

- 2009: A project describing electronic tagging of hospital equipment proposed to extend tagging to enable tracking of staff. It was suggested that this could be combined with time and motion studies to optimise work flows
- 2009: a proposal to expand a company-sponsored health and wellness trial program in which staff recorded health indicators and received feedback on their health status, to enable linking and cross-analysing of data on absenteeism and productivity to provide managerial insights into productivity

# A critical discourse

- Health informatics professionals are integrally involved in creating the systems facilitate expanded use of personal health information
- Changes in how information is used may impact differently on different groups
- If the interests of all stakeholders are to be considered, it is important to consider the implications of proposed expanded uses

- Rather than relying only on rules and laws, which tell us what should or should not happen, we should design systems that determine what can and cannot happen  
(Armstrong, 2003)

Thank you

