Personal health information, privacy and surveillance

Do we need a critical voice?
Personal Health Information

• Amongst the most sensitive of personal information
• An ever-more valuable resource
  – The value of health information today lies increasingly in secondary applications
  – Secondary uses include service planning and evaluation, policy development, health and medical research and commercial applications
The problem

• Many uses of personal health information bring significant benefits but may also carry unintended negative consequences, often as a consequence of function creep
  • Genetic screening programs of newborns infants (Mariner, 2007)
  • Healthy Kids Check program for three year olds (Butler, 2012)
  • Canadians blocked from entering the United States after their records of mental illness were shared with the US Department of Homeland Security (Bridge, 2011)
A complex issue

• What is considered appropriate monitoring activity in one context may appear to be intrusive surveillance in a different context

• Boundaries between consensual monitoring and non-consensual surveillance are blurred

• The move from consensual monitoring to non-consensual surveillance can occur almost unnoticed
Responsibility of the health informatics community?

• The health informatics community is concerned with developing the sophisticated information systems that facilitate collection, manipulation and dissemination of increasing amounts of personal health information.

• The community also contributes to high-level discussions regarding policies and guidelines for managing access to, and use of this information.

• The views of the community therefore have potentially significant consequences.
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)

• **Australasian College of Health Informatics:**
  – The health informatics professional should respect the rights and interests of others (2012)
The study: discourses in health informatics

- Sought to identify the views of the health informatics community in Australia about expanding use of personal health information
- Analysis of health informatics literature
  - Not from the peak bodies
  - HISA conference papers: the voice of the community
  - Based Michel Foucault’s discourse analysis methodology
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
<table>
<thead>
<tr>
<th>Discourse</th>
<th>Scope, focus, issues</th>
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</thead>
<tbody>
<tr>
<td>Scholarly discourse</td>
<td>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</td>
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<tr>
<td>Management discourse</td>
<td>Discussed information and information management systems as supporting good management practices</td>
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<tr>
<td>Health technology discourse</td>
<td>Represented the discipline as primarily concerned with identifying and resolving the technical problems associated with the construction and implementation of clinical computer/information systems</td>
</tr>
<tr>
<td>Clinical informatics discourse</td>
<td>Focused on the activities of clinicians in the immediate clinical environment</td>
</tr>
<tr>
<td>Nursing discourse</td>
<td>Spoke of health informatics in terms information management for nursing, practice</td>
</tr>
<tr>
<td>Populations discourse</td>
<td>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</td>
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<tr>
<td>Discourse</td>
<td>Basis for support for expanded use of personal health information</td>
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<td>---------------------------------------</td>
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<tr>
<td>Scholarly discourse</td>
<td>Acknowledged the need to protect privacy, while arguing strongly for access to personal information for research purposes</td>
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<tr>
<td>Management discourse</td>
<td>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</td>
</tr>
<tr>
<td>Health technology discourse</td>
<td>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</td>
</tr>
<tr>
<td>Clinical informatics discourse</td>
<td>Located privacy issues within the context of clinical care where professional practice and codes of ethical behaviour prioritise privacy and confidentiality</td>
</tr>
<tr>
<td>Nursing discourse</td>
<td>Located privacy issues within the context of clinical care where</td>
</tr>
<tr>
<td>Populations discourse</td>
<td>Argued for expanded access to both de-identified data and personal health information for public health research and policy development</td>
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</tbody>
</table>
Findings

• Dominant health informatics discourses focus on practical issues of managing access to personal health information for purposes legitimated by law and policy makers rather than on ethical questions about the intent and consequences of these uses.

• They do not ask the questions ‘how much is too much?’ , ‘when does monitoring become surveillance?’ ‘what are the implications or possible consequences of these activities?’ , or ‘how are these expanding uses able to occur?’

• There is evidence of function creep in the activities of health informatics professionals.
Incremental 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 for monitoring the assessment skills and care delivery of each practitioner as well as giving an effective method of review
Opportunistic 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.
The need for a critical discourse

• Health informatics professionals are integrally involved in creating the systems facilitate expanded use of personal health information

• Health informatics professionals can’t always leave critical discussion to the peak bodies

• Each of us has a responsibility to actively critique the implications of the systems we create
Thank you