Everyone's a winner, baby? (Risks relating to potential uses of health information in Australia)

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The vision

- There is a vision that the electronic health record may deliver the health informatics promise of more effective and efficient health services, better quality care and long-term positive health outcomes for individuals and the community as a whole

Reality check

- At the same time, this vision must be tempered by the realisation that we need to manage some very real risks inherent in the implementation of an electronic health record
- Privacy and confidentiality are significant issues that need to be addressed

The focus

- The majority of discussions around privacy, confidentiality and access to information focus on minimising the risk of unauthorised and illegal use of information contained within the electronic health record

Assumptions

- These discussions are underpinned by the assumptions that
  - Those determining appropriate and legal use of information will get it right
  - What can legally be done with information is always in the interests of the individual
- This may not always be the case

Demands

- The New South Wales Ministerial Advisory Committee on Privacy and Health suggested:
  - As electronic health records become more comprehensive and more accessible, there may be increasing pressure and demands placed on the information by non-health care bodies (for example insurers, employers, law enforcement agencies and some government agencies) [1]

One example

- The proposed uses of this information may not always be in the interest of the consumer
  - The West Australian police recently used Guthrie test samples to match DNA samples taken from a crime scene [2]
  - This may appear to be a legitimate use of such data – we all want to see criminals apprehended

Widening access

- Would it still be acceptable if content from medical records were provided to insurance companies or employers?
- Or even, as flagged in a recent report published in the United States, for homeland security and other surveillance activities? [3]

Consider

- We need to be aware that health data that people are happy to share now may become a liability in the future
- Many of the proposed secondary uses have a great initial attraction, but others clearly require that much greater deliberation be carried out in a public setting

Tackling the issues

- The consequences of these potential legitimate uses of data are not being fully discussed
- Comments on the proposed Australian Department of Human Services Access Card noted that
  - the government had played a clever game of avoiding engagement on privacy issues [4] and
  - the more details that are settled, the more certain is the loss of control over our personal information [5]

Our responsibility

- We are not advocating cessation of work on the electronic health record, but these potential uses of health information need to be considered
- There is a need for a wider, fully informed public debate
- It should be a debate in which we, the health informatics community, have a responsibility to speculate, debate and engage both our own members and the wider community

References

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