



Submission to the Department of Health and Aging concerning the exposure draft legislation for the Personally Controlled Electronic Health Record System (PCEHRS).

The New South Wales Council for Civil Liberties (CCL) is one of Australia's leading human rights and civil liberties organisations. Founded in 1963, NSWCCL is a non-political, non-religious and non-sectarian organisation that champions the rights of all to express their views and beliefs without suppression. To this end the NSWCCL attempts to influence public debate and government policy on a range of human rights issues by preparing submissions to parliament and other relevant bodies.

The CCL is grateful for the opportunity to make this submission.

Background

The CCL has expressed its concerns about successive variations of the proposal to establish a PCEHRS for some time (at least since a New South Wales Government proposal in 2001). We have been and are concerned that any system risks a severe invasion of privacy with possible consequences for a person's employment, eligibility for government assistance, social life, insurance and ability to negotiate a loan. These consequences may be worse if a record is faulty. Lives are shortened by such things.¹

We are particularly concerned that a loss of trust in the ability or willingness of a medical practitioner to keep a patient's health status confidential will lead to patients not being willing to expose sensitive information to a practitioner.

Thus while we accept that the PCEHRS may save lives, especially in emergency situations, it also has the potential to cost lives.²

We have been aware of the various submissions which the Australian Privacy Foundation has made of successive proposals, in particular the detailed submission of May 2011 and supplementary submission June 2011 and we generally support their concerns.

The draft bills

We recognise that the draft bills contain significant safeguards against misuse of the PCEHRS. Those safeguards are, in our view, vital. We note in particular that patients will be able to decline to opt in to the system, and that they will be able to determine what parts of their medical history will be accessible to whom. They will be able to correct their own records.

¹ See for instance Yale News, May 23 2002, <http://news.yale.edu/2002/05/23/rising-unemployment-causes-higher-death-rates-new-study-yale-researcher-shows>,

² For a useful discussion see Tom L. Beauchamp and James F. Childress, **Principles of Biomedical Ethics**, Fifth Edition, Oxford University Press, New York 2001 pp. 306ff.



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We understand that the Australian Medical Association has expressed concern about this safeguard. We support strongly the entitlement of patients to make such corrections. General practitioners and medical specialists are not immune from mistakes, and they should not believe in the infallibility of their own records. (Indeed, it is our experience that doctors are taught not to trust each other's diagnoses, but to check them themselves.) Despite the high level of integrity in the profession, there are also those who are tempted to cover up their mistakes.

Further, as noted in the Introduction above, the consequences of a faulty record may not be limited to mistaken diagnosis and treatment. It is vital that patients have access to their records, and can correct them.

For similar reasons, the PCEHRS should provide for immediate notification to a patient if the security of their record has been compromised. The CCL notes that access to medical records could be worth a considerable amount of money to certain businesses. We are not convinced of the effectiveness in these circumstances of penalties in deterring crime. We welcome however the measures contained in the draft bills to ensure the security of patients' records.

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