



**Australian
Privacy
Foundation**

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The Hon. John Hatzistergos, MLC
Minister for Health
Parliament House
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NSW Healthelink trials – putting privacy at risk

We are writing to express our profound disappointment in the design of Healthelink, and to urge you to delay the commencement of trials until patients' privacy and security can be genuinely assured.

On 10 March 2006 a regulation was made at your request, to overturn the requirement to obtain a patient's express consent before they are placed in a system of shared electronic health records.

The Health Records and Information Privacy Regulation 2006 was made in relation to the first trial of the NSW Healthelink system, which we understand is due to commence this Thursday 23 March.

Having removed the need for patients' express consent, the Department of Health will thus automatically enrol certain people in the Hunter and Western Sydney areas into a central Healthelink database. Healthelink will then automatically collate those patients' health information from various healthcare services.

The patient's Healthelink record will include not only summaries of their visits to GPs and hospitals, but also pathology records such as blood test results, and records of consultations with mental health, sexual health / family planning and counselling services.

Health consumers must then proactively un-enrol themselves if they do not wish their records to be viewable by all participating health practitioners (not just their own practitioners), from dentists to social workers. Yet even then, information about people who "opt out" will still be kept by the Department of Health.

The Australian Privacy Foundation is appalled at this complete abrogation of promises made by the NSW Government to protect patients' privacy.

We submit that this regulation:

- is possibly unlawful, being directly inconsistent with the aims of the Act by negating Parliament's intentions the very first time they are put to the test
- undermines doctor / patient confidentiality
- is opposed by peak patient, doctor and public interest bodies
- is contrary to the recommendations of the NSW Health Council (the Menadue Report) and the NSW Ministerial Advisory Committee on Privacy and Health Information (the Panacea or Placebo Report), and
- exposes patients to undue risks to their privacy and personal security.

On behalf of NSW patients whose privacy and security will be placed at risk as a result, we urge you to delay the commencement of the Healthelink trials, until such time as the trials can proceed purely on the basis of first obtaining a patients' express consent to be included.

We do not accept assurances made by your predecessor Minister for Health, now Premier, Mr Lemma, that Healthelink protects patient privacy because it is "voluntary". The NSW Ministerial Advisory Committee on Privacy and Health Information, when engaged to deliberate upon this issue prior to the current health privacy laws being drafted, specifically concluded that an "opt out" system cannot be described as a "voluntary" one.

Nor do we agree with Mr Lemma's comparisons between Healthelink and online banking.

We do not know of any bank which compulsorily collects sensitive personal information about people who may or may not be its customers, designs an open system in which any employee of that bank (or any other bank) can view a person's records simply by searching on their surname, then asks people to proactively "opt out" of online banking entirely if they don't like it.

Furthermore, banks are increasingly aware of the dangers of "phishing", in which customers' online banking login/password combinations are obtained by unauthorised parties. Banks are already investing in more sophisticated methods of data security and e-authentication. Yet Healthelink has been designed on the basis that both clinicians and patients need only a login/password to access both health records and identity information, including patients' home address and home telephone number.

Finally, we do not agree with assertions by your Department that consumers and clinicians prefer "opt out" over "opt in". In fact the published views of the two peak organisations representing health consumers in NSW (NCOSS) and clinicians (the AMA) state the opposite – they are in favour of "opt in".

Although the trials of Healthelink are being used to make decisions about what consent model should be used for the entire NSW population, we understand that NSW Health has not consulted people aged between 15 and 65, and/or people who are *not* frequent health system users, about the Department's preference for "opt out".

Yet the rest of the population will likely have very different views to the under 15s and over 65s on the privacy risks versus the health benefits of electronic health records.

In particular, people aged 15 to 65 are more likely to have concerns about:

- the sensitivity of sexual health information, including contraception, infertility, terminations, infectious diseases, and sexual abuse
- the sensitivity of drug and alcohol information, and
- potential employment and insurance uses of their health information.

We believe that a system of electronic health records needs to work for everyone – both in terms of delivering the health benefits, but also in terms of minimising the privacy risks.

The model should be designed to promote the health benefits for those most likely to benefit, *and* be designed to minimise the privacy risks to those most likely to suffer a privacy impact.

Minister, we submit to you that Health*elink* has been designed with complete disregard for the law, expert advice, doctor and patient opinion, previous Government promises, and industry practice with regards to protecting privacy and data security.

The long-term success of Health*elink* will depend on the level of trust placed by health consumers in the system and its administrators and users. The promised health benefits of electronic health records will surely be lost if administrative convenience is allowed to trump patient privacy and security, for a system which is not trusted will be subverted or ignored.

We urge you to repeal the Health Records and Information Privacy Regulation 2006, and order your Department to go back to the drawing board to design Health*elink* to work the way it was intended and promised – to deliver health benefits without risking patient privacy.

Further background material is attached for your information.

Yours sincerely

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Chair, Australian Privacy Foundation

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About the Australian Privacy Foundation

The Australian Privacy Foundation is the leading non-governmental organisation dedicated to protecting the privacy rights of Australians. We aim to focus public attention on emerging issues which pose a threat to the freedom and privacy of Australians.

Since 1987 the Australian Privacy Foundation has led the defence of the rights of individuals to control their personal information and to be free of excessive intrusions. We use the Australian Privacy Charter as a benchmark against which laws, regulations and privacy invasive initiatives can be assessed. For further information about us see www.privacy.org.au