20 March 2006

Mrs Jillian Skinner Shadow Minister for Health Parliament House Macquarie Street SYDNEY NSW 2000

Re: NSW Healthelink trials

Dear Mrs Skinner,

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

This regulation was made in relation to the trial of the NSW "Healthelink" system, which 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 thus include not only summaries of their visits to GPs and hospitals, but also pathology records such as blood test results and x-rays, 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 being 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.

We submit that this regulation:

- is possibly unlawful, being directly inconsistent with the aims of the Act by negating Parliament's intentions
- o undermines doctor / patient confidentiality
- is opposed by patient and doctor representatives
- is contrary to the recommendations of the Menadue Report and the NSW Ministerial Advisory Committee on Privacy and Health Information, and
- o 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 consider moving a disallowance motion in relation to the Health Records and Information Privacy Act Regulation 2006.

Further background information is attached for your information.

Yours sincerely

Anna Johnston Chair, Australian Privacy Foundation

Phone: (02) 9432 0320

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.

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