



**Australian
Privacy
Foundation**

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The Hon Peter Dutton MP

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House of Representatives
Parliament House
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Peter.Dutton.MP@aph.gov.au

Dear Minister Dutton,

Re: Privacy and the PCEHR record

The Australian Privacy Foundation (APF) is the country's leading privacy advocacy organisation. I am writing in my capacity as Chair of the Health Committee of the APF.

I refer communication received by a patient who was asked to sign up for the PCEHR by her General Practitioner (GP) during a medical consultation. The patient was anxious that her concerns did not receive adequate response when she consulted both her GP and the Office of the Australian Information Commissioner.

Her concerns are as follows:

“Information uploaded to my PCEHR will be kept for 30 years post mortem or 130 years if DOD unknown.

If I change my mind and wish to withdraw, while the information can be "cancelled", it is not deleted: it will still be kept as above and may still be accessed.

While we would expect that the information could be used only for health care, this is not so: it may be used also for law enforcement, medical indemnity insurance and other purposes.

Health care providers sign a participation agreement, which assigns all intellectual property rights to data uploaded to the PCEHR to the government. These rights can never

be revoked, even on termination of the agreement.

Full access to my data may be gained from any PC in the country configured with NASH certificate, by invoking the "emergency access" criterion.

There is no guarantee that the government (System Operator) will not attach unspecified additional data to my PCEHR, without my knowledge or consent.

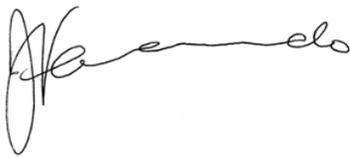
With the possibility of the Minister's review resulting in the scrapping of the PCEHR system now or later, there is uncertainty over what will happen to my data.

With less than 1% of those who have registered actually uploading shared health summaries, what use is the system anyway?

If I were in your position [the patient's GP], I would be looking at the penalty provisions, which can amount to over \$17,000 for individual and over \$85,000 for body corporate and to whether my indemnity will cover me against possible action in connection with PCEHR."

The individual concerns expressed here are indicative of several recent communications with the APF from clinicians, other patients and information technology specialists. They are consistent with emerging global and regional frameworks under the auspices of the Organisation for Economic Cooperation & Development and the European Commission, for example regarding consent. They are also consistent with disquiet expressed by health service professionals, government agencies and consumers in the United Kingdom – disquiet that is significantly impacting the establishment of the UK e-health system and of initiatives such as care data that are potentially valuable but will not be viable in the absence of support from health professionals and consumers.

Yours sincerely



Chair, Health Sub Committee Australian
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