



Consumers
Health Forum
of Australia

17 February 2012

Mr James Catchpole
Committee Secretary
Joint Select Committee on Cyber-Safety
PO Box 6021
Parliament House
CANBERRA ACT 2600

Dear Mr Catchpole,

Inquiry into Cybersafety for Senior Australians

The Consumers Health Forum of Australia (CHF) welcomes the opportunity to provide input into the *Inquiry into Cybersafety for Senior Australians*, which was referred to the Joint Select Committee on Cyber-Safety on 23 November 2011.

CHF is the national peak body representing the interests of Australian healthcare consumers. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems. Our comments are focused on enhancing safety and security for older consumers in relation to the Personally Controlled Electronic Health Record (PCEHR), which will be operational from July 2012.

CHF's work in this area draws on consultation with our membership, which includes organisations advocating for older consumers, disease specific groups and networks, state and territory peak consumer organisations and individual consumers. CHF's submission also draws on consultations undertaken through our *Facilitating Consumer Input on the PCEHR* Project, consumer input on CHF's response to the Concept of Operations, and a dedicated consumer forum on legislative issues relating to the PCEHR held in October 2011.

CHF's submission raises a number of issues relating to safety and the PCEHR, including:

- Authorised collection, use and disclosure of consumer health information
- The PCEHR complaints mechanism
- The PCEHR audit trail
- Notification of PCEHR breaches.

Authorised Collection, Use and Disclosure of Consumer Health Information

From July 2012, consumers registering for a PCEHR will be able to provide access to the information in their record for secondary purposes. Some consumers consulted by CHF have expressed concerns that users could be coerced into permitting access to their record when this will not be in their best interests. Older Australians, particularly those who lack computer and online health literacy skills, may be particularly vulnerable.

In response to this issue, some consumers called for measures to specifically exclude the use of the information by third parties including employers and insurers. It has also been suggested that additional legislative measures could be necessary to prevent the information in the PCEHR from being used to discriminate against a consumer, potentially following the model of the US *Genetic Information Non-discrimination Act 2008*.

CHF recommends that the committee safeguards to prevent the misuse of PCEHR information by third parties, such as employers or insurers.

The PCEHR Complaints Mechanism

The complaints mechanism for the PCEHR will be crucial to ensuring the safety and security of consumer health information, and will be of particular interest to older Australians, who are likely to be high-end users of the health system. Throughout our consultations, consumers have emphasised the importance of ensuring that there is a single, clear avenue for making complaints that is accessible to consumers. Consumers have not articulated preferences for what the preferred point of entry should be, except to suggest that the success of the proposed management of PCEHR complaints by Medicare Australia should be reviewed. Consumers should also be provided with educational materials about the right to complain and how to do so, and be assured of prompt responses to complaints.

CHF recommends that the Committee explore the management of the PCEHR complaints mechanism, and the possibility of a review of Medicare Australia's role as the complaints body.

At CHF's forum on the Exposure Draft legislation for the PCEHR system, consumers noted the fact that those dissatisfied with the response from the PCEHR System Operator could have their complaint escalated to the Information Commissioner for investigation. However, participants considered it essential that the Information Commissioner be provided with additional resources in order to conduct these investigations.

CHF recommends the allocation of additional resources to the Office of the Australian Information Commissioner to ensure it has the capacity to conduct investigations on behalf of consumers.

The PCEHR Audit Trail

The provision of an audit logging function capturing any changes, updates or unauthorised viewings of a PCEHR, will be important to ensure security and build consumer confidence in the system. According to the Explanatory Memorandum of the *Personally Controlled Electronic Health Records Bill 2011*, the PCEHR system will provide an audit trail showing the organisations that have accessed their records but not the healthcare professionals responsible for the breach.

Consumers consulted by CHF considered that this would make it extremely difficult to identify any unauthorised viewings of their PCEHR, and will significantly undermine the safety of their record. CHF therefore considers it essential that consumers will be able to view an activity history for their PCEHR, including which individuals have accessed their record.

CHF calls for the audit trail to provide consumers with information on individual health practitioners who have accessed their record.

Notification of Breaches

Until recently, it was CHF's understanding that consumers will be notified of major breaches relating to their record, but not necessarily more minor ones, as this will be left to the discretion of the PCEHR System Operator. However, evidence provided by the Department of Health and Ageing at a hearing on additional estimates on Wednesday 15 February 2012 suggested that consumers will be notified of all breaches. CHF would like to see this matter clarified, and stresses the centrality of such notifications to the safety and security of the system.

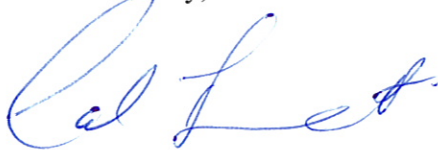
When consulted on the Exposure Draft legislation, consumers felt strongly that it should not be left to the discretion of the PCEHR System Operator to determine what constitutes a major breach. This issue was also cited as key to consumer confidence in the system. They called for consumers to be notified of **all** breaches, whether major or minor.

CHF recommends that consumers be notified of *all* breaches of the PCEHR system affecting their record.

CHF considers these aspects of the system critical to the safety and security of consumer health information. We hope the Committee will take this opportunity to explore consumer safety issues around the PCEHR.

CHF welcomes the opportunity to provide input into the Inquiry and we look forward to reviewing the Committee's report on this issue.

Yours sincerely,



Carol Bennett
CHIEF EXECUTIVE OFFICER