

Consumers e-Health Alliance Submission to the Joint Select Committee Inquiring Into CyberSafety For Senior Australians

Background

The Consumers e-Health Alliance (CeHA) is an alliance comprising 22 leading chronic illnesses and conditions organisations (Attachment 1).

CeHA notes that several submissions and presentations to the Inquiry into cyber safety for senior Australians have given attention to the impending launch of the Personally Controlled Electronic Health Record (PCEHR).

It is apparent that the terms of reference of this inquiry are particularly relevant to the development of the electronic health record and we appreciate the opportunity to comment on this important issue.

Summary of recent activities relating to the PCEHR

The National eHealth Transition Authority (NEHTA) conducted a stakeholder summit on 12/13 April 2012 and prior to this held a pre-summit consumer workshop on 3/4 April. CeHA representatives participated in both these events.

The proposed PCEHR governance arrangements and the combined issues of safety, security and privacy along with the actual content of one's record were the principal aspects to attract the attention of attendees. Consumers, including senior Australians will want to choose whether to "Opt-In" to such a record.

Former Australian Privacy Commissioner, Mr Malcolm Crompton, made the point in support of the "Opt-In" decision, that an "Opt-Out" approach could not be justified whilst ever the current top down governance arrangement was preserved. This is a view which CeHA strongly supported in its submissions to the Senate Inquiry into the proposed PCEHR legislation.

Issues of concern

The consumer community was not adequately consulted prior to the release of the proposed underlying rules and regulations for the PCEHR and these are now held in dispute by many stakeholders because they are very heavy-handed for a system which has not yet even completed its design phase. They do not keep things simple, an objective which has been CeHA's catchcry, but rather make a currently widely accepted process unduly complex for all parties.

CeHA is very concerned about the risk of cyber fraud upon the aged community who are to be a priority group for PCEHR take up. Our concern has also been very widely expressed by other organisations through their submissions to this inquiry, but we particularly draw attention to those by Australian Federal Police (No. 20), Australian Institute of Criminology (No. 12) and Australian

Crime Commission (No.9).

Furthermore, it seems to us that the DOHA, NeHTA and Telstra inputs to the cyber safety inquiry reflect a self-protective bias which fails to recognise their responsibility to educate the emotionally susceptible senior citizen community (amongst others) on how to use the system safely to guard against the very great risks involved in exposing their health records to unauthorised scrutiny. For example, it is now common to receive a stream of scam emails seeking information from consumers about log-in details to entities such as banks, telcos and the like. Just imagine the potential harm for vulnerable aged people that could arise from their unwitting release of information that would provide such accessibility to their Health Record, let alone access to their normal financial interactions in daily life.

In addition, there is community concern about the possibility of hacking into health record repositories or unauthorised access for improper purposes, but there should possibly be even more concern about "identity fraud." We refer to this only as an example of many issues, known and probably unknown, which have not yet surfaced in part due to the lack of quality cross community consultation but concern about which exists across the community. Our pleas about this are not new but apparently are not heard or understood within government. This has long been a global problem which has not been recognised within the implementation of this critical e Health tool. It is an issue which has been assigned resolution within the dominant technology silo when it is one that deserves broader public policy attention and understanding.

It is also timely to ask what national clinical safety governance for e-health should look like in Australia, as e-health can sometimes lead to patient harm or death through problems in design or operation. This concern is very aptly illustrated by an editorial "A Call for National e-Health Clinical Safety Governance"¹ in the Medical Journal of Australia editorial of 16 April, 2012 written by eminent academics and clinicians: Enrico Coiera, Michael Kidd and Mukesh Haikerwal (Attachment 2).

The authors note that when harm occurs, it may extend to large groups of patients as the result of a single error. They also note that e-health is currently unregulated and unmonitored in Australia and there is no organisation with either the expertise or mandate to govern system safety. They argue that only by governments committing to a set of principles to safeguard whole of system safety can an eHealth system be adequately managed.

CeHA is also concerned about the broader scope of the proposed initial governance of the PCEHR which places all aspects of system operation in the hands of the Secretary of the Department of Health and Ageing (DOHA). Whilst there is some mention of a review to enable community involvement in governance after two years there is little comfort in having the system operator report to an internal and merely advisory governance process until an independent governance entity can be conceived and implemented. To have all performance aspects including content quality, safety, security and privacy operating within the same overall governance structure cannot be regarded as good practice.

Conclusion

CeHA recommends that the Joint Select Committee notes the breadth and depth of issues surrounding cyber safety for senior Australians in eHealth, and encourages the government to hasten slowly in its implementation of these new technologies. We also hope that better

1 <https://www.mja.com.au/journal/2012/196/7/call-national-e-health-clinical-safety-governances>

governance arrangements can be put in place to ensure that all risks relating to safety and security of seniors' information in the emerging e-health environment can be fully recognised and satisfactorily addressed with due collaboration with the community.

In this context we are recommending that **“the PCEHR Legislation and Regulations be amended so that the proposed Independent Advisory Council advises the Minister, rather than advising the System Operator.”**

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Introduction to Consumers e-Health Alliance

The Consumers e-Health Alliance (**CeHA**) is not formally incorporated at this stage, but its current partners comprise 22 leading chronic illnesses and conditions organisations along with some individual members. Refer below for listing of CeHA Associates.

Peter Brown – Cancer Voices Australia - convenor.

Steering Committee

Peter Brown (Cancer Voices Australia)

Russell McGowan (Health Care Consumers Association)

Anna Williamson (Leukaemia Foundation of Australia)

Eric Browne, carer (formerly involved with HealthConnect)

Dr Janet Wale (Cochrane Consumer Network)

CeHA is a collective of consumer oriented organisations and people who have displayed active positive interest in the e- Health program. Our initial activities are to highlight the major blockages to effective implementation i.e. Ownership, Governance, Leadership and the community wide 4C's:-

Communication | Co-operation | Collaboration | Coordination.

CeHA seeks agreed standards at all levels and for all affected community sectors to be appropriately represented at the same table at the same time. CeHA provides the avenue for the tabling of ideas, concerns, needs, information on e-health in which development we have a common interest and which directly affects the individual lifestyles of every citizen including their individual health needs at all times.

CeHA ASSOCIATES as at 1/4/2012

Alzheimer's Australia	Health Consumers Queensland
Aged Care Association Australia - NSW	Health Consumer Council - WA
Arthritis Australia	Health Consumers of Rural and Remote Australia
Asthma Foundation	Kidney Health Australia
Australian Diabetes Council	Leukaemia Foundation of Australia
Australian Lung Foundation	National Heart Foundation
Cancer Council Australia	National Stroke Foundation
Cancer Voices Australia	PRA Mental Health Recovery
Cochrane Consumer Network	Private Mental Health Consumer Carer Network (Australia)
Health Consumers Alliance - SA	Tasmanians with Disabilities
Health Care Consumers Association - ACT	The Country Women's Association of Australia