Consumers e-Health Alliance

to the

Senate Community Affairs Legislation Committee inquiry

regarding the provisions of the Personally Controlled Electronic Health Records Bill 2011 and the provisions of the Personally Controlled Electronic Health Records (Consequential Amendments) Bill 2011

Supplementary submission March 2012.

This supplements our initial submission No. 37 and our answers to questions on notice. It addresses the current status of the PCEHR implementation.

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

| Communication | Co-operation | Collaboration | Coordination |

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Current PCEHR status

[*This supplements our initial submission No. 37 and our answers to questions on notice.*]

The overseas experience suggests that whatever their targeted benefits may have been, the importance of providing clinical usefulness first, is a recognised priority of shared electronic health record systems. If we accept the lesson from this experience, then the PCEHR is putting the cart before the horse and may deter the take up of the PCEHR proposal as it stands. This seems to be recognised but not acknowledged as such within the current wave 1 and 2 lead e-health sites. (refer Pulse+IT magazine February 2012 interviews).

Discussions in Canberra over the past week and a consideration of Hansard's record of the second reading speeches of the PCEHR Legislation Bills has clarified a central issue for us. It is apparent that the community at large do not understand what will be available within the PCEHR from July 1, 2012.

It is clear that the PCEHR concept has overwhelming support amongst the Parliamentarians. This accords with all the NeHTA surveys of the broader community. However it seems that the Parliamentarians who are being ask to vote on the enabling legislation have not been adequately advised in detail what it is they are being asked to endorse.

For example, as it is also the case with the community, one of the members thought that the PCEHR would contain all the data from the existing service provider records including the GP – local clinical record, so as to comprise a consolidation of all relevant prior patient history.

He: “Oh, does this mean there will be two separate records?” Us: “That is our understanding.”

Shock horror! In this reaction, he is not alone.

The NeHTA promotional flyers have obviously and understandably been accepted at the Parliamentary level as factual but probably with a few outstanding technical glitches, as is to be expected. This also accords with community understandings.

We are finding that even an elementary explanation of the situation brings an immediate reaction for an apparent need for delay of the legislation to allow a closer review and better understanding of what it is that e-Health can really do, and how a successful implementation could be achieved at a more acceptable cost and in complete safety. What is needed to address this is to initially convert selected existing records to a sharable electronic format, and to use these as a basis for further agreed changes rather than reinvent the wheel without step by step testing and acceptance.

It is our view that the existing record and proposed governance plans are inappropriate to deliver such an approach and is the underlying cause why:-

1. The estimated cost has escalated beyond rational belief; whilst
2. The targeted design for July 1 has sharply declined in terms of both meaningful content and timeliness.

It seems apparent to us that the Parliament may be being asked to act on legislation in the absence of correct and complete information and/or the withholding of it across these and maybe many other factors.

We suggest there is a serious challenge of what to do about this.

We are very concerned that NeHTA did not deem it necessary that the lead operating managers appear at the Senate hearing to fully explain the status of the PCEHR program.

We have also reached the conclusion that jurisdictions are far from being in a position to contribute or participate in any meaningful way with the PCEHR from July 2012.

We consider that the status of the PCEHR design and build needs to be verified independently before the legislation proceeds.

The sheer size and organisational inertia of jurisdictions, their already heavily committed programs of infrastructure refresh, and their complex workforce management issues, often mean that a commitment to the PCEHR in practice must fall well short of the expectations held by many.

We would like to see an independent assessment of the capability and cost of jurisdictional programs that connect with the national PCEHR system and when they will be targeted to occur.

The reviews we recommend should ideally extend to take into account the capabilities and preparedness of private hospitals, Medicare Locals, Local Hospital Networks and allied health providers to participate in the evolving PCEHR program, so that ultimately, the PCEHR can actually achieve what it should achieve – to bring the information from all health care participants into a coherent record for truly patient-centred care.

-- END of SUBMISSION --