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Dr Ian Holland
Committee Secretary
Senate Community Affairs Committee
By email: community.affairs.sen@aph.gov.au

Dear Dr Holland,

Health Care Consumers' Association Submission to the Senate Community Affairs Inquiry into the Personally Controlled Electronic Health Records Bill 2011

Health Care Consumers' Association (HCCA) was formed over 30 years ago to provide a voice for consumers on local health issues and now provides opportunities for health care consumers in the ACT to participate in all levels of health service planning, policy development and decision-making.

In 2009, HCCA established an *eHealth Consumer Reference Group (EHCRG)*, in response to strong interest from consumers and their desire to be at the centre of the decision and policy-making processes. Membership has increased steadily and the *EHCRG* now comprises some 20 individuals, including senior ACT Health Directorate staff. The *EHCRG* has provided an excellent forum for HCCA and ACT Health Directorate to develop a solid, collaborative relationship, through a shared interest in, and commitment to, eHealth. The comments in this submission reflect the views of the members of the *EHCRG*.

HCCA welcomes the introduction of the *Personally Controlled Electronic Health Records Bill 2011* and this opportunity to submit comments on the *Senate Community Affairs Committee Inquiry into the Personally Controlled Electronic Health Records Bill 2011 and one related bill*. In general terms, we believe the PCEHR should provide a powerful tool to enable consumers to manage their own health care needs with the assistance of their chosen clinicians. For this reason, it will be essential that personal control of the record remains a key feature of the EHR.

There are considerable risks inherent in the proposed implementation strategy and some key issues which need to be addressed or clarified, particularly in respect of the purpose of the EHR, privacy, access, security and governance.

We stress the importance of:

- A clear understanding that the purpose of the EHR is to optimise a consumer's healthcare outcomes by improving co-ordination of care and trusted communication between clinicians and consumers

- the pivotal role of the PCEHR in improving patient safety and quality in health care
- consumer participation in the governance and ownership of the PCEHR system
- operational transparency and accountability
- establishment of a clear policy on consumer access to the system.

We believe it is imperative that the functionality of the system is sound in the lead-up to the initial roll-out of the PCEHR system and are concerned that the time frame of July 2012 is too short to achieve this. We would like to see more evidence to show that all the necessary mechanisms are in place to achieve a successful eHealth initiative nationally, rather than just a determination to meet a politically imposed deadline. In order to limit the possibility of failed implementation, we believe that a rigorous risk analysis needs to be applied to implementation strategy, with adjustments to the implementation timeframe as necessary.

HCCA believes consumers should have the opportunity to provide input into the long-term governance structures of the system, through a public consultation process, and that it should ultimately be overseen by an independent statutory authority with technical competence in which consumer perspectives are represented, in addition to those of clinicians, national, state and local governments and private healthcare providers.

We would like to see more detail about informed consent and access arrangements, to reassure consumers that their personal information is safe. We would like the Bill to specify exactly which government authorities will have access to the PCEHR system and an explanation of the audit arrangements in place to advise consumers when, why and how much of their personal data has been accessed.

HCCA understands why an “opt in” (rather than an “opt out”) policy has been adopted for consumer participation in the system and continues to support it, although we remain concerned that allowing clinicians to withhold records from the system may disadvantage consumers who choose to opt in and that some form of mechanism to limit this possibility needs to be incorporated in the EHR implementation. This, we believe, will enable it to better cater to consumer needs.

Overall, we welcome the Bill and would welcome the opportunity to engage in the Inquiry at a public hearing.

Yours sincerely,

Darlene Cox
Executive Director

24 January 2012