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PCEHR/HI Discussion Paper Feedback,
Department of Health
Email: ehealth.legislation@health.gov.au

Re: Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper 2015

The Health Care Consumers' Association (HCCA) is the peak health consumer organisation for the ACT and the wider Capital region. We provide a voice for consumers on health issues and provide opportunities for health care consumers 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*.

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.

We stress the importance of:

- a clear understanding that the purpose of the EHR is to optimise consumer's health care 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, and
- establishment of a clear policy on consumer access to the system.

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.

We support the implementation of a consistent eHealth record system for all Australians. This is a missing element of our health system if we are to achieve an integrated system that will optimise our health outcomes. A common experience of consumers is the frustration of having to repeat key information about themselves, their medical history, and current medications to multiple clinicians.

There has been a fair degree of frustration at the pace of the work to date. The Consumers E-Health Alliance (CEHA) published a paper in December 2014 that expressed their concern about the progress made, given the amount of time and money expended so far. Many of our members share this view. We are very keen to see the eHealth agenda realise the benefits that have been long promised and are interested in contributing to this.

Our response to the paper is attached. We would welcome an opportunity to discuss this further.

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'Darlene Cox', written in a cursive style.

Darlene Cox
Executive Director

25 June 2015



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Response to Electronic Health Records and Healthcare Identifiers: Legislation Discussion *Paper 2015*

25 June 2015

Contact
Darlene Cox
Executive Director

Response to Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper 2015

The Health Care Consumers' Association (HCCA) is the peak health consumer organisation for the ACT and the wider Capital region. We provide a voice for consumers on health issues and provide opportunities for health care consumers to participate in all levels of health service planning, policy development and decision-making.

We consulted members of our EHealth Consumer Reference Group in preparing this response.

General comments:

Participation

Consumers remain firmly of the view that the utility of the PCEHR will be significantly enhanced if the providers are all participating, and consumers are advised of those providers that have opted not to participate. The gaps in the records from some providers not participating, particularly specialists, are a major impediment to the utility of the PCEHR.

The Consumers Health Forum, the national peak consumer organisation of which HCCA is a member, has been advocating for an opt out system for PCEHR over many years and has seen this as the most effective way of rolling out the scheme. Our membership has been more cautious and supported an opt-in system initially to test the issues relating to governance, privacy and security. We concede that the current opt-in approach has proven to be very slow in recruiting consumers and providers to participate.

One of our strongest concerns with the proposal is that the clinicians participating are provided with the option to withhold records from the system which may disadvantage those consumers who choose to opt in. We have received feedback from consumers who are frustrated that their PCEHR is not useful to them as their general practitioner and private specialists do not upload their information to it. In the ACT we value the functionality across ACT Health to contribute discharge summaries.

Over the past five years there has been significant changes in the way in which information technology has infiltrated our lives. Increasing numbers of people are shopping online, looking up health information, maintaining their personal finances and carrying out a wide range of personal administrative tasks. It is important to consider eHealth within this context.

We are very supportive of trials that will include an opt-out approach for both consumers and health service providers. We are especially interested in trials of the use of PCEHR in the aged care context. We have had preliminary discussions with a number of aged care providers as well as ACT Government Office of Ageing, the Health Directorate and ACT Medicare Local and would very much like to see the ACT identified as a trial site.

Governance

HCCA believes consumers should have the opportunity to provide continuing input into the long-term governance structures of any system implemented. Based on previous experience in eHealth, HCCA will be seeking consumer representation to provide input at all levels, in the transition to a PCEHR system, and into the future, on the Australian Commission for EHealth, Jurisdictional Advisory Committee and Board level of the Australian Commission of EHealth.

Specific comments:

There are number of comments relating to specific parts of the discussion paper:

3.1.2 Definitions: health related programs

There are mixed views in our membership on the extension of the definition to include “health related programs”. One of our members, who does not support this change, said: “The use of the health identifier for social service programs undermines personal control and privacy. It is also viewed by many as the introduction of ‘data linkage by stealth’.”

There are security and privacy concerns that data could be transferred from the PCEHR to other programs with lesser controls and make the data available to non-healthcare providers.

Other members are supportive of this development and see that there are benefits in having a more integrated approach to human services, including health services as well as home and community care. It is clear that the security and audit trails of any related programs using this linkage be upgraded to align with the PCEHR so that any breaches can be identified and prosecuted and that the penalties for breaches be commensurately increased.

We recommend that records be retained of who has access to the health identifiers and related data, to ensure that a consumer’s data is not targeted either in the data base or in transmission.

3.2.1 Disbanding current arrangements

The safety of the system is of significant importance to consumers. While the discussion paper mentions that “an independent assurer reporting directly to the minister” will be appointed, the scope and access of the assurance is not provided and we would welcome additional information to make it clearer.

3.3 Opting Out In Trial Regions

Individual Consent

In the Opt-In model a participant may choose to have the Medicare and PBS history data loaded. The Discussion paper proposes that the Medicare data be loaded by default. If the Medicare data is to be loaded by default for all participants recruited in the Opt-out regime, there should be a facility to remove the data if so requested.

Secondary use of Information

There are mixed views in our membership regarding the secondary use of data. Some are of the view that individual consent should be obtained before the data is de-identified and provided for secondary use and that individual consent be required for linkages of de-identified records. Others within our membership are interested to have this embedded in the system, as long as there are safeguards in place to ensure records are de-identified.

We hold concerns about the level of risk for linkages that will enable individuals to be identified from the context and information in the records. We think that consumers need to be included in any decisions regarding this matter.

3.4 Obligations of Parties.

One of our members who has had long term involvement in eHealth has expressed particular concerns:

“In previous consultations, consumers have advised the Department of the risk posed by repository operators. Repository operators could cease providing their services. This would leave a gap in the PCEHR records of numerous consumers and destroy the integrity of the PCEHR system. This would mean that consumer records will have missing data resulting from two separate causes: providers are not participating; and then we have missing records as a repository operator withdrew its service. The Commonwealth should include in the legislation that that any repository operator wishing to cease operation, should provide the data to the Commonwealth to host the service.

3.4.7 Obligations for System Operator to Notify Decisions

We do not support the proposal that “Written notification would only be used if no other forms of communication are practical or appropriate.” Some consumers still prefer to have written communication so this should be the primary means of communication for those consumers. In the situation where a cancellation or suspension is to take effect,

it is more significant that there is clear audit trail of the advice provided. We do not agree that a verbal communication “by phone” is sufficient nor appropriate in this situation.

3.5.2 Temporary Suspension of Access to a PCEHR

It is not clear what appeal right and notification will be provided to re-instate the access by the representative and the timeframe for this to occur if the appeal is successful.

3.5.3 Collection Use and Disclosure of Information

Healthcare Provider Directory (HPD)

We support the publication of organisations in the HPD. The Opt-out principle should apply to providers with regard to their participation in the Healthcare Provider Directory.

Handling of Healthcare Identifiers by Prescribed Entities

We have a degree of concern about the proposal to allow “certain other records to use healthcare identifier”. We think this requires additional discussion with consumers. One member expressed that “these linkages are undermining individual control and undermining privacy”. We are concerned about the risk that the linkages will enable individuals to be identified from the context and information in the records.

Information Commissioner’s Use of Health Care Identifiers

We support this proposal. This should be extended to those parties that will be required to oversee safety and quality of the systems and usage.

Data

Clinical safety issues need to be reported to external independent agencies. We would like to see stronger links to the Australian Safety and Quality Commission in Health Care and the Health Performance Authority.

Handling by AHPRA

We support the two-way flow of information to and by AHPRA and correction of errors at source.