Submission to the Senate Community Affairs Committee's Inquiry into the Provisions of the *Personally Controlled Electronic Health Records Bill 2011*

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Overview

Medibank is pleased to provide this submission to the Inquiry into the provisions of the *Personally Controlled Electronic Health Records (PCEHR) Bill 2011*. This submission expands on our previous submission on the exposure draft of the PCEHR Bill.

Medibank and *healthbook*

Medibank is Australia's largest integrated private health insurance and health services group. We have been providing health insurance to Australians since our inception in 1975 and currently cover 3.7 million members, equal to 31% of the national private health insurance market. In addition to our resident members, Medibank also covers over 200,000 overseas visitors and students and provide access to life, pet and travel insurance.

In the last three years, Medibank has undergone a significant transformation, growing the role we play in our customers' health and evolving into a provider of broad range of health services. In doing so, we have become Australia's largest provider of telephone based health advice, triage, counselling and referral services. We deliver these services 24 hours a day, seven days a week across Australia and New Zealand, safely handling more than two million calls a year and delivering high quality health advice to more than 25 million people.

We deliver the Australian Government's *healthdirect Australia* and the Victorian Government's NURSE-ON-CALL services. Medibank is also the service delivery provider for the Australian Government's *after hours GP helpline*, the national service that connects callers to a GP at times when their usual doctor may not be available, including at nights, on weekends and on public holidays. We also partner with a wide range of clients including public sector healthcare organisations, national and state governments to deliver telehealth services. With almost 15 years of service delivery, Medibank has a track record of responsiveness, excellent customer service, unparalleled safety and quality. The outcomes we have delivered directly result in more appropriate utilisation of primary care and hospital based emergency services.

One of our guiding principles has always been that members' information should be captured appropriately and used to help deliver timely and effective health outcomes. In July 2011, Medibank successfully bid to receive some funding from the Australian Government to partially fund the building of *healthbook* – a personally controlled, customer centric eHealth record. Medibank is extremely proud to be one of the nine pilot programs established by the Government and managed by the National electronic Health Transition Authority (NeHTA).

healthbook will be a key platform for Medibank's engagement with, initially, 1,000 of our chronic disease management customers. Those customers will use it to enter both their current status of health and specific actions under a medically developed Care Management Plan. They will be assisted in the management of their disease or condition by Medibank Health Solutions nurses, who will also be able to view *healthbook* so as to support the member with the activities outlined in the Care Management Plan. Over time, *healthbook* will be made available to Medibank's 3.7 million customers to enable them to control their personal information, enroll in preventive health management programs and manage their ongoing health.

Specific issues in relation to the PCEHR Bill

Medibank is pleased to note that a number of issues raised in our submission on the exposure draft of the PCEHR have been addressed. Issues that we feel still need to be addressed are summarised below.

Definitions

The definition of *healthcare* appears to be too limited by its present reference only to 'illness' and 'disability'. Private health insurance legislation refers to 'disease, injury or condition' which is

broader than the definition in the present Bill, although it still has some limitations as the word 'condition' connotes a negative or problematic health condition. This creates difficulties in the following circumstances:

- Fertility - as being relevant to any procedure like a vasectomy or the prescription of contraceptive medications;
- The treatment of the fertile partner for conception purposes where the relevant condition affects the other partner;
- A healthy donor undergoing surgery or a procedure connected with that donation;
- Voluntary (and not clinically indicated) circumcision; and
- Healthcare that is for aesthetic or cosmetic purposes.[1]

Medibank recommends that, in addition to the above, the following are incorporated into the definitions:

- Preventive health is a fundamental aspect of modern healthcare and should be explicitly included in the definition; and
- The definition of 'health information' refers to information about 'the health or disability of an individual' while the definition of 'healthcare' refers to diagnosing an 'individuals illness or disability'. It would be helpful if these definitions used consistent terminology.

Use of information by researchers/healthcare service planning
The information stored in the PCEHR system is likely to be of significant interest to medical research centres and organisations interested in accessing de-identified information for the purposes of health and medical research.

It is also likely that healthcare information available in PCEHRs will be extremely relevant to localised healthcare service planning. For example, de-identified data may help the newly established Medicare Locals to more accurately predict appropriate service types and need. Provision should be made in the legislation to facilitate access to health information for these purposes.

Use of information by other organisations
Most private health insurers now offer their members access to preventive health programs to promote better health. Access to PCEHR information may also therefore be relevant for private health insurers enabling them to identify members who may benefit from access to such programs. While an individual consumer can potentially disclose his or her own PCEHR information to an insurer for such a purpose, any use of that information by that insurer (or anyone else not a participant in the PCEHR system) currently represents a breach of the legislation. A further limitation stems from the fact that the individual consumer must make the disclosure and cannot authorise the intended recipient to access it. This limitation on the powers of the consumer to authorise access to, and use of their health record does not appear to be consistent with a *personally controlled* record and should be addressed to enable effective use, subject to the individual's agreement, of their health information.

Liability
It remains unclear to what degree healthcare professionals will be held responsible for a patient's safety when relying on information uploaded by another healthcare professional to a PCEHR.

[1] While there are good reasons that cosmetic treatments are excluded from other healthcare legislation relating to funding, there seems to be no reason why clinicians providing cosmetic treatments should not be able to access information regarding their patients' previous medical histories, known allergies and current medical condition.

Concerns exist about liability if the recorded information is inaccurate, not up to date or not visible to the healthcare professional. It may be appropriate for healthcare professionals who rely on information in a PCEHR to have the benefit of an express statutory permission that allows them to assume the information in the record is accurate and reliable unless they have reason to suspect the contrary.

Copyright
Medibank notes paragraph 45 (c) of the PCEHR Bill but queries whether sufficient protection is given to persons who may access and use information uploaded to the PCEHR system so that their use of it, consistent with the legislation, involves no breach of copyright or related moral rights obligations.

Application of state legislation
It would be useful to have further clarification as to the way in which repository operators will be subject to state legislation governing medical records including when and how they apply. For example, there is currently a lack of clarity as to whether the health information of an individual who has elected to cancel their PCEHR registration should be retained within the system. Whilst the *Privacy Act 1988* would suggest that the record should be deleted because the collector of personal information no longer has a requirement to maintain it, clarification about the obligations of registered repository operators in this instance would be helpful.

Disclosures required by law
At present, clause 69 refers to disclosure only to Courts or Tribunals. However, in certain legal proceedings, disclosure is required to be made directly to a party, proceedings or to a prospective party to possible proceedings. In cases where disclosure is required to be made to a Court, there is often a procedural requirement that it also be disclosed to one or more parties or to be conveyed to a Court through the party serving the relevant order. The entire clause would therefore be better constructed if it referred to disclosure being made pursuant to an order of a Court or Tribunal or pursuant to the Rules of Court or similar subordinate legislation.

Breaches by participants in the PCEHR system
Clause 75 appears to impose obligations on entities *other than individuals*. If that is not correct, then drafting conventions dictate that such a provision should be accompanied by an express acknowledgement that the obligation does not override the right not to self-incriminate. If this reading *is* correct, then we query whether there is a corresponding practice that such legislation should also state that there is no defence to the obligation merely because it would involve a disclosure that may tend to criminate the entity concerned.

Implementation considerations
Medibank has a number of broad concerns that may be addressed when the rules accompanying the PCEHR Bill are determined and implementation planning is finalised. Issues that need to be considered during these processes are outlined below.

Engaging the primary healthcare sector
Medibank strongly advocates the importance of robust engagement with general practitioners and allied healthcare providers across the primary health care system, including medical and nursing colleges in Australia. Primary healthcare practitioners will need to be informed, educated and supported to implement and maintain use of the PCEHR. It would be useful if this engagement was observable by the healthcare industry and included clear information about:

- Consultation opportunities;
- Transition timing and processes;
- Marketing to support implementation; and

- Training opportunities for the sector.

Opportunity to be consulted on rules
Medibank would be pleased to have an opportunity to comment on the form and content of proposed rules, and any regulations, that will be developed to support implementation of the PCEHR legislation. It is our view that input from the healthcare industry would greatly enhance the implementation process and ensure that rules are realistic and support widespread adoption of the initiative.

Access by service users
The draft Bill is largely silent on whether health care service users will be able to upload information to their own PCEHR. While Medibank understands that this will be part of the system design, it is important that the use of this information is clarified in accompanying rules. Service user input into their PCEHR will allow health practitioners to more effectively liaise, monitor and support health prevention and management activities.

Monitoring and evaluation
There needs to be clear information about the benefits of the program for both patients and practitioners, and processes in place for monitoring uptake and usage of the PCEHR. Early development and distribution of a monitoring and evaluation framework would provide the healthcare industry with confidence in the long term viability and sustainability of the program.

Ongoing funding of the program
Information and consultation is needed in relation to the funding mechanisms that are being considered to support implementation. Primary care practitioners, in particular, need greater clarity about how the program will be funded and what implications this may have for their own practice or business operation.

Planning and funding to support leadership throughout the implementation process
A number of organisations are providing early, high level leadership in relation to the PCEHR system and consideration should be given to funding these organisations throughout the implementation process to:

- Publish information about their experiences and involvement, to date, of the PCEHR system;
- Provide advice and support to other organisations engaging in the PCEHR system; and
- Provide advice and information to Government that will enhance the implementation process.

Consumer capacity to contribute to PCEHR
Consumer engagement with the PCEHR is vital to successful implementation and will drive a higher volume of public adoption of the program. Medibank would like to see evidence of robust engagement with consumer representative organisations specifically in relation to the design, delivery and use of the PCEHR.

Medibank would welcome the opportunity to provide further information or detail to the Inquiry should that be helpful.