APS Response to the

Senate Community Affairs Committee on

Healthcare Identifiers Bill 2010 and Healthcare Identifiers (Consequential Amendments) Bill 2010

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March 2010

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The APS thanks the Senate for the opportunity to comment on this Bill. The Society has maintained an involvement in the emerging e-health agenda and is particularly interested in the nature of the electronic health record and how this might impact on the personal information of community members and the private and public practitioners whose services constitute much of the record. The Society's concerns centre on processes of access by other health providers, protecting the privacy and rights of healthcare recipients and the preserving the integrity of the health records. The implications for infrastructure costs and disruption to healthcare providers are also of concern to the Society's members.

The Society has been a supporter of the e-health programs and, like other professional bodies and healthcare organisations, has waited to see the nature of the proposed process and the progress of the program features as they unfold. This Bill is critical and pivotal to progress and the APS is supportive of its aims and intentions.

In an earlier submission to NEHTA in August 2009, the APS raised some concerns that have been mostly met (and satisfactorily) by the considerations and measures in the Bill. These were:

- need for administration by a Statutory Agency;
- that identifiers do not constitute a means for identity checks;
- the basis on which The Agency or Health Provider Organisation may disclose an IHI;
- need for precise definitions of *healthcare* , *healthcare providers* and *healthcare services* based on activities undertaken by professionals, rather than by settings in which they occur;
- a definition of *specialisation* that does not limit itself to only medical specialisation*;*
- the management of variation between jurisdictions on privacy legislation;

Each of these matters was either addressed explicitly in the proposed legislation or omitted in a way that resolved the concern. There were, however, two matters also raised that were not addressed and seem to need to be dealt with at some stage. They were:

- Alteration to records: by whom and when? This would appear to be a matter for later legislation or regulation and will be put aside in this paper;

- Creating alternative "personal" logs. This does seem relevant at this stage. The issue about which the APS commented was whether a HPI-I or an HPI-O can create their own logs of IHIs recording individuals' access or interactions. This is an important issue as such "digital footprints" can be used to profile individuals' health service access and utilisation – and could constitute a fundamental breach of their privacy. A compromise needs to be achieved between such public health "data harvesting" exercises and the potential misuse of individual data associated with IHIs. Moreover, the mere knowledge that such "data harvesting" exercises can take place could potentially prompt some people not to access services or refuse to reveal their IHI, thereby undermining the quality and integrity of data obtained.

The Terms of Reference

The specific Terms of Reference before the Inquiry are addressed below.

1 *Privacy Safeguards in the Bill*

The issue of consumer right to privacy and confidentiality has been a central issue for the *ehr* since its inception as an idea and now as it becomes a reality. The APS has submitted to both NEHTA and Senate Inquiries about this matter and it still remains a central concern. Many of these concerns are ameliorated by the commitment of NEHTA and the recommendations of the National Health and Hospitals Reform Commission that allowed for patient control of the record. Although it is not quite clear how this will work in practice and how it will resist practitioner parochialism and professional territorialism but the principle is sound and essential to protecting privacy concerns.

The APS continues to retain concerns about issues within the privacy domain. Although these are not the subject of this inquiry it is useful to highlight some of these as a context in which the health identifier is being considered. Some of these are:

- How do the needs of patients of the mental health service sector protect their rights to confidentiality and privacy and withstand the pressure to centralise records and information, particularly in the public health sector?
- How will practitioners in both private and public sector providing services to patients with mental health disorders or other socially sensitive conditions be allowed to protect their records from the pressure to centralise those records or allow approved access? The APS has advised its members to maintain sub files of confidential clinical notes and sensitive information that are secure and not part of the central or accessible record. This is being strongly resisted by a medically-dominated system not familiar with stigmatisation of conditions or the inclusion of third party sensitive information in records;
- How will the issue of genuine informed consent be managed around the process of the patient/client granting permission for access to records or deciding to quarantine information in situations where the power inequalities threaten, if not negate, informed consent?
- What safeguards will be developed to resist third party intrusions into the records (eg insurance companies, employers and even the Courts) when in an electronic form it will be so easy to share or forward records of assessments, investigations or services.

The clauses of the Bill that deal with protection are sufficiently explicit and detailed to form a basis for protection of privacy. The pivotal role of the Privacy Act and its intended revisions to accommodate the IHI and the ehr is endorsed and goes some way to providing reassurance that privacy will be genuinely protected.

2 *Operation of the Healthcare Identifier Service*

There is considerable sense in the proposal that the Healthcare Identifier service should be, and will be, managed by Medicare Australia. It is also obvious that such a proposal is open to misunderstanding in the community where people recognise that Medicare Australia holds considerable data about their personal usage of health services funded by the government which they may not want confused with the details of their clinical record. It will be essential that the limitations and virtual firewalls place between the two data sets needs to be made much clearer, presented regularly and openly to the community and perhaps even made mention of in the legislation.

In addition the relationship between the health identifier and the national health registration system also needs some clarification. This is made specific mention of below, but it seems important that while the relationship between Medicare Australia and the health identifier system is being discussed, the relationship to be national health registration identification number system should also be referred to.

3 *Relationship to national e-health agenda and electronic health records.*

The creation of a set of health identifiers for recipients of services, providers of services and organisations that provide services is understood to be a vital first step in creating the electronic health record and progressing the national e-health agenda. However, it is far from unclear how the whole process of patient centered management, multiple records of services, security of access and the facilitation of the upgrade of provider electronic systems is to be achieved. To that extent the APS supports this legislation but waits for both the associated regulations and the future outputs from NEHTA and other bodies to answer the multitude of questions surrounding the national e-health agenda.

Specific Matters in the Bill

The APS wishes to draw the following to the attention of the Senate Committee:

1. S.9 of the Bill allows both the service operator (Medicare Australia) and a national registration authority to assign healthcare identifiers to healthcare providers. This raises the following issues:
    a. Will both entities be working from a common standardised set of identifier datasets. That is, healthcare identifiers issued from Medicare Australia will be compatible with those issued from national registration authorities. The APS believes this should be explicit in the Bill.

b. It is apparent from the Bill, based on the definition of healthcare providers, that the national registration authority will be required to issue healthcare identifiers to registrants with the following registration categories:
    i. Student registration;
    ii. Non-practising registration;
    iii. Provisional registration;
    iv. Limited registration, of which, there are four sub-categories; and
    v. Specialist registration.

   However, it is not clear if the healthcare identifiers then issued will be temporary in nature or will be that person's permanent identifier and will have life beyond the initial period (e.g. when a registrant move from limited registration to full or general registration).

2. S.9 (4) of the Bill gives Medicare Australia to mandatorily assign (impose) healthcare identifiers to both providers and recipients. However, it is not clear if such "enforced" healthcare identifiers will be used as a "once off" or be "recycled" for later use. For instance, a "dummy" number could be allocated where a service recipient so desires and that number may well be discharged later at the choice of the recipient. What then happens to the dummy number: recycled or never used again? The APS recommends "once off" use.

3. S. 13 of the Bill authorises the national registration authority to disclose "information that the national registration authority has that relates to a healthcare identifier". If, as it appears, this clause is to allow national registration authorities to pass on information such as conditions of registration to Medicare Australia, should then 1 (a) and (b) be separated by "*and"* (not "*or"* as it currently stands) and (b) should be changed to read *"…relates to a healthcare provider identifier"* (not *"healthcare identifier"* so as to remove any ambiguity). These changes are important as some conditions may limit the geographical location of services delivered and the type of clients such registrants may have contacts with.

4. S.18 of the Bill (a), the words "(if any)" seems not necessary as s.9 (4) of the Bill empowers Medicare Australia to mandatorily assign healthcare identifiers.

The APS await the regulations with interest.