Submission by the Australian Psychological Society to the Senate Inquiry into the

Personally Controlled Electronic Health Records Bill 2011 and one related bill

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Introduction

The Australian Psychological Society (APS) thanks the Senate Community Affairs Committee for their invitation to provide a submission to the Inquiry into the Personally Controlled Electronic Health Records (PCEHR) Bill 2011. This submission builds on the APS submission to the Department of Health and Ageing on the PCEHR Exposure Draft Bill and will highlight three areas of particular concern to the APS and its members:

1. The need for more robust complaint handling structure within the System Operator;
2. The ability of consumers to exclude parts of their PCEHR to all healthcare providers, even in cases of emergency or serious threat; and
3. The ability of all verified healthcare providers to upload records to a consumer's PCEHR with appropriate consent.

Then some other related issues are also raised.

1. Governance and complaints handling

The APS believes that robust and transparent governance is fundamental to the successful operation of the PCEHR. There are three broad categories of governance. Those that relate to the:

1. Operational infrastructure of the PCEHR, such as contract management, procurement of systems and asset management;
2. Technical specifications of the PCEHR, such as various standards relating to compliance and system specifications, including the National Authentication Systems for Health (NASH); and
3. Interface between the PCEHR and other systems or entities, such as training and education, independent audit and monitoring and clinical safety.

While the Exposure Draft outlined the roles and functions of the Jurisdictional Advisory Committee (Division 2) and the Independent Advisory Committee (Division 3) in relation to the PCEHR, it remains unclear to what extent the Commonwealth is taking a leading role in the governance in relation to the operational infrastructure of the PCEHR (category 1) and as a major stakeholder in the latter two categories described above. The APS has previously suggested that such functions require a cross agency committee, at least involving the Department of Health and Ageing, the Department of Human Services and the Department of Broadband and the Digital Economy.

Moreover, it is not clear who consumers can turn to when they have issues or complaints against the PCEHR System Operator. Given that the System Operator will most likely be a Government agency, stringent and transparent regulatory oversight must be in place so that consumers can be assured that issues such as breaches in privacy/inappropriate access, clinical governance, data security/accuracy and investigation are addressed with specialist input and with appropriate legislative instruments where necessary.

It would be preferable for consumers to have a single point of entry for complaints regarding their PCEHR. A one-stop-shop will assist and direct consumers with complaints to the appropriate authorities. However, the APS urges caution in adopting such an approach without careful planning, staff training and appropriate communication between the complaint lodgement agency (the one-stop-shop) and

the complaint handling agency (various government departments and other agencies). Recent experiences, particularly during the period immediately after the establishment of the Australian Health Practitioner Regulation Agency (AHPRA), suggest that a considerable transition period (including piloting and training) is required for the one-stop-shop complaint lodgement agency. This will ensure that consumers have their complaints relayed and directed in a timely and appropriate manner and are not unnecessarily delayed, adding to their frustration and injustice.

2. Placing consumers at the centre of care

It is no accident that the words "Personally Controlled" precede "Electronic Health Records". The PCEHR is designed from the ground up to place consumers at the centre of the system by giving them explicit control over what information healthcare providers can upload, share and access. While this will not be an issue for the vast majority of consumers, it is of the utmost importance to some of the most vulnerable groups in the community – some of whom may benefit the most from the PCEHR. Therefore the APS strongly supports the notion of consumers opting-in for their PCEHR and exercising control around access.

The PCEHR Concept of Operations, which informed the development of the Exposure Draft, outlined an "effective removal" option for consumers to hide or delete certain health records from open access. It is not clear whether the Shared Health Summary part of their PCEHR will still include a reference to such a particular health service (e.g. will there be a reference to a psychiatric report, but the actual report is "effectively removed" by the consumer so its contents cannot be accessed by some healthcare provider?) - a critical issue in protecting the privacy of consumers and needing resolution with regard to the PCEHR. It is recognised that there is an underlying assumption that consumers who exercise the "effective removal" appreciate that the removed record may contain information critical to their ongoing healthcare needs. While the APS appreciates that this is not ideal from a clinical safety perspective, it feels that it reflects a reality currently facing all healthcare providers: they are not provided with the full clinical histories of all consumers at all times. For this reason, allowing consumers that level of personal control is fundamental.

Through ongoing consultations with bodies such as the National E Health Transition Authority (NEHTA), the APS understands that despite their removal, effectively removed records can still be obtained from the System Operator by the consumer or even under court orders (i.e. the "effectively removed" record is still archived by the Systems Operator and not deleted or erased from the system). The extent and management of such access needs clarification.

The APS notes that there was no mention of such a feature in the Exposure Draft (ie. "effective removal"). However the Department of Health and Ageing and NEHTA have assured the APS that the "effective removal" option will be part of the PCEHR system, but under Rules and Regulations to be developed once the Bill is passed. The APS sees the "effective removal" option in the PCEHR as critical in maintaining privacy of consumers, and urges the Government to ensure such an option is detailed in the Rules and Regulation once the Bill is passed.

In the PCEHR legislation issues paper, the APS raised the following "*on the issue of data security, it would be reasonable to expect servers which host various data repositories to be located in Australia and that any backup servers also to be based*

in Australia. While the internet is "borderless", having repository servers based in Australia will facilitate any forensic auditing and investigative processes". This has not been addressed in the Exposure Draft. Again, the APS urges the Government to have this issue covered in the Rules and Regulations once the Bill is passed.

3. Making provisions for all healthcare providers to contribute to the PCEHR

There are four stated aims of the PCEHR Bill:

1. Help overcome the fragmentation of health information;
2. Improve the availability and quality of health information;
3. Reduce occurrence of adverse medical events and duplication of treatment; and
4. Improve the coordination and quality of healthcare provided to consumers by different healthcare providers.

In order to achieve these inclusive aims, it is vital that all healthcare providers have the ability to contribute to the PCEHR of consumers. Moreover, these aims represent an explicit endorsement of the contribution of all healthcare providers to consumers. The APS is therefore wholly supportive of Section 39 of the Exposure Draft which outlines the specific conditions for providers to upload records into the PCEHR.

While the Shared Health Summary portion of the PCEHR should be uploaded by the consumer's nominated healthcare provider (a GP in most circumstances, but may be a registered nurse or Aboriginal Health Worker), other providers, such as psychologists, should be able to upload other records such as Event Summaries and Specialist Letters to the PCEHR with consumer consent – as described under S.39 (3) (b) of the Exposure Draft. This would require some investment by providers, which, in turn, will require support from the Government. Why this is so, is discussed in detail below.

4. Other issues for consideration

The following issues are not directly related to the Exposure Draft, but they do have implications for the uptake and utilisation of PCEHR after July 1, 2012. The APS makes these comments in order to facilitate the "buy-in" by all providers, and to ensure that consumers are not disadvantaged through an inability to engage or by non-participation by other providers, such as psychologists, allied health, dentists, nurses and medical specialists.

4.1 Consumers seeking anonymous care

Part 3 of the Exposure Draft implies that only consumers with "proven" identities will be allowed to register for a PCEHR. Does this exclude consumers using pseudonyms, as may be in the case of domestic violence or witness protection programs? There is no provision for consumers to seek anonymous care and have a PCEHR. While this may be done to prevent certain undesirable activities, such as identity fraud, it also has the unfortunate effect of isolating specialist healthcare providers (who are working with those with mental health issues, for instance) contributing to the PCEHR and the ability of consumers to register for anonymous healthcare and have a PCEHR.

4.2 Support for organisations contributing to consumer care via PCEHR

The July 1, 2012, start date for the PCEHR will be significant event in the e-health reform journey. There will be a significant push by informed consumers for all their

usual healthcare providers to be PCEHR ready and compliant. While providers in general practices, through Practice Incentive Payments (PIP) and other mechanisms, are well resourced to deal with such demands, Allied Health providers (and others see above), will be forced to bear the increased business costs.

This was well addressed by a Booz Company report, which stated *"costs and benefits are often misaligned in healthcare: Stakeholders that are required to invest significant resources in e-health may only reap a smaller portion of apparent benefits, and those with the most to gain may incur fewer costs."* and "*governments are best positioned to intervene in this distorted market and better align costs and benefits."(from http://www.booz.com/media/file/Optimising_e-Health_Value.pdf)*

A fully operational PCEHR will most benefit consumers through coordinated healthcare via quality information. Much of that healthcare is coordinated via general practice, and therefore GPs are the next highest to benefit from PCEHR. This, however, may not apply as much to other providers. Yet it is these providers who will be forced to bear increased infrastructure costs through compliance with the PCEHR with no compensation, support or incentives from Government.

While a National Change and Adoption Partner for the PCEHR has been appointed, the focus to date has been on the GP sector, which already receives generous support as mentioned above. Moreover, it has not been made clear by the Department of Health and Ageing, what support, if any, will be offered to healthcare providers post July 2012. Given the non-existent support for allied health to date, this issue requires urgent attention by the Government.

Many allied health providers work in their own practices, either alone, or as part of a multi-practitioner (but single discipline) practice. They contribute to the overall care of consumers through privately funded, third-party funded or a number of Medicare programs. A recent report into the e-health readiness of allied health by McKinsey Asian Pacific found high levels of attitudinal e-health readiness among allied health providers and high levels of trust placed by these providers in their professional associations. These two factors suggest that the Government, through its agencies, must work collaboratively with these professional associations as a matter of priority to ensure the wider adoption of PCEHR by all health providers. Consumer demand in healthcare, particularly in the primary health sector, requires extensive input from allied health providers. Without meaningful and prompt engagement of these providers, consumer care will be less than optimal and diminish the stated aims of the Exposure Draft legislation.

Conclusion

The APS strongly supports the rollout of the PCEHR for consumers by July 1 2012. However, there are three major barriers:

- lack of a robust and transparent governance framework for the PCEHR, particularly a complaint handling structure for consumers;
- adequate guarantees that the "Personal Control" aspect is emphasised through an opt-in system, access management options and the preservation of a consumer-friendly option for "effective removal" of health records for consumers;
- lack of assurance that all verified healthcare providers have equal abilities to contribute to the PCEHR.

The APS urges the Government to work collaboratively with various allied health associations well in advance of the July, 2012, starting date of the PCEHR in order to ensure that consumers are able to benefit from input from all healthcare providers under the PCEHR.

About the APS

The Australian Psychological Society (APS) is the peak national body for the profession of psychology, with over 20,000 members, representing over 60% of registered psychologists, and including nine specialist colleges. As the representative body for psychologists, the APS has access to a vast pool of psychological expertise from both academic and professional service delivery perspectives. The APS has responsibility for setting professional practice standards, providing ongoing professional development and accrediting university psychology training programs across Australia. It is represented on a number of advisory groups involved in the planning, implementation and ongoing monitoring of Government policy initiatives. Constant communication with its members, plus access to high level psychological expertise and detailed involvement in Government initiatives, enables the APS to significantly influence the psychology workforce to ensure best practice in health service delivery.

The APS has a proud history of working in collaboration with Australian Government departments and other organisations in the successful delivery of policies and programs aimed at improving the health outcomes of Australians.