Personally Controlled Electronic Health Records Bill 2011 and one related bill

caah
the children's hospital at Westmead
NSW Centre for the Advancement of Adolescent Health

Submission to

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600 Australia
via email: community.affairs.sen@aph.gov.au

About NSW CAAH

The NSW Centre for the Advancement of Adolescent Health (NSW CAAH) works in partnership with NSW Health and other sectoral stakeholders to improve the health and wellbeing of young people aged 12 - 24 in NSW. The key focus areas of NSW CAAH include developing information and resources; capacity building to increase workers' skills and confidence in adolescent health; supporting applied research; advocacy & policy development to increase leadership and action for adolescent health.

Thank you for the invitation to provide a submission to the Standing Committee on Community Affairs to assist its inquiry into the provisions of the *Personally Controlled Electronic Health Records Bill 2011 and a related bill.*

Benefits of personally controlled electronic health records to young people

Personally Controlled Electronic Health Records (PCEHR) have many potential benefits to young people. Electronic records are also well suited to young people as many have good access to technology and are tech savvy.

Young people are often mobile, changing health care providers due to moving geographically, having difficulty navigating the healthcare system or locating a health care provider whom they can trust and develop a rapport.

Young people may not have their Medicare Card with them when accessing healthcare – in this case the health care provider can access their PCEHR to gain access to their Medicare number. This would be of benefit.

An electronically held record can assist with the transition to independence as adolescents take on responsibility for their own health and healthcare access, by providing a record of past issues and treatments.

The inclusion of the capacity in the PCEHR for young people to write their own notes, which can be shared with a health professional or kept private, is commended. This encourages young people to have an active involvement in maintaining their health and a sense of ownership of their record.

Adolescents are often concerned about confidentiality when accessing health care and this affects their willingness to engage with health professionals. The PCEHR rightly allows young people to consent to their own health care and have access to their records from the age of 14.

The inclusion of a mature minor clause is of benefit for young people who have a need and the capacity to make decisions affecting their healthcare. It is appropriate that a written assessment by a health professional be provided as evidence.

It is commendable that young people will be actively informed by the System Operator at the age of 14 that they can take control of their PCEHR, and at the age of 18 be informed that the young person's parents or guardians will cease to be authorised representatives.

It is also beneficial that young people will be able to access services anonymously using an alias should they choose to do so.

Issues to be further explored

A number of issues and opportunities warrant further exploration.

Currently in Australia, the ages for consent to health care vary from State to State. These variations are mapped in the *Adolescent Health GP Resource Kit* (Chown et al, 2008). There would be benefit in having consistent laws across Australia as this is currently confusing for health professionals and would hinder smooth implementation of the PCEHR. It is not clear if the *Personally Controlled Electronic Health Records Bill 2011* achieves this consistency.

Young people can create their own PCEHR from the age of 14 but require a Medicare card to do so. As they can only get their own Medicare card from 15, this may be an issue to resolve.

Education on obtaining a Medicare card for young people at age 15 years is currently often limited to the individual initiative of schools and medical centres. The PCEHR may provide an opportunity to inform young people of their right to a Medicare card from the age of 15. Further, the issuing of cards to young people could be combined with the PCEHR to make the process more straight forward for young people.

Young people require identification to create a PCEHR. This may be an issue for some young people, particularly those experiencing homelessness. Currently young people do not require ID to access health care.

The range of health professionals included should be expanded so that the PCEHR can encompass a holistic record of care. For example at *headspace centres* young people see allied health professionals such as Social Workers and Psychologists. These health professionals should also be able to access and contribute to the PCEHR.

References

Chown P, Kang M, Sanci L, Newnham V and Bennett DL (2008) *Adolescent Health: Enhancing the Skills of General Practitioners in caring for young people from culturally diverse backgrounds. A Resource Kit for GPs, 2nd Edition.* Transcultural Mental Health Centre and NSW Centre for the Advancement of Adolescent Health, Sydney.

[See http://www.caah.chw.edu.au/resources/gpkit/08_Section_2_chap_6_medico-legal_issues.pdf]