australian nursing federation

Submission to Department of Health and Ageing in response to the Personally Controlled Electronic Health Record (PCEHR) System Legislation Issues Paper

August 2011

Lee Thomas
Federal Secretary

Yvonne Chaperon
Assistant Federal Secretary

Australian Nursing Federation
PO Box 4239 Kingston ACT 2604
T: 02 6232 6533
F: 02 6232 6610
E: anfcanberra@anf.org.au
http://www.anf.org.au

1. Introduction

Established in 1924, the Australian Nursing Federation (ANF) is the largest professional and industrial organisation in Australia for nurses, midwives, and assistants in nursing, with Branches in each State and Territory of Australia. The core business for the ANF is the professional and industrial representation of our members and the professions of nursing and midwifery.

The ANF has a membership of over 200,000 nurses, midwives and assistants in nursing. Our members are employed in a wide range of settings in urban, regional, rural and remote locations, in both the public and private health and aged care sectors.

The ANF participates in the development of policy relating to: nursing and midwifery practice, professionalism, regulation, education, training, workforce, and socio-economic welfare; health and aged care, including reform agendas, community services, veterans' affairs, occupational health and safety, industrial relations, social justice, human rights, immigration and migration, foreign affairs and law reform.

Given that nursing and midwifery form the largest cohort within the health and aged care sectors, and are the most geographically dispersed of all health care workers, the ANF is vitally interested in the development of health information management in the electronic environment. This extends to the involvement of consumers of health care in their own records.

The ANF has been participating to the work of the National E-Health Transition Authority (NEHTA) and to the development of electronic health records. The following comments are provided in response to the release of the Personally Controlled Electronic Health Record (PCEHR) System Legislation Issues Paper.

2. Personally Controlled Electronic Health Record (PCEHR) system

The ANF continues to support the introduction of an electronic health records system. Such a system will bring benefit for both health professionals and consumers of care. Chief among the benefits is the timeliness of information and the removal of the need for consumers to endlessly repeat their health history.

Essential to the success of the Personally Controlled Electronic Health Record (PCERHR) System will be access control processes which are manageable for health professionals and consumers (so that the system really is 'personally controlled'). This will mean crafting legislation which gets the right balance of privacy and sharing of confidential information with ease of use and management controls. If the system proves too difficult for any of the stakeholders then the degree of 'opt-in' will be compromised.

The ANF submission to follow addresses questions posed in the PCEHR Issues Paper.

Q1 Are there other potential participants in the PCEHR System and what is their role?

From a nursing and midwifery perspective the ANF does not consider that there are any other potential participants in the PCEHR system beyond those listed on page 13 of the Issues Paper.

Q2 Should portals for consumer registration be provided by organisations other than health related organisations, including government organisations?

The ANF suggests that there may need to be additional organisations involved as portals for the consumer registration process other than health related organisations. Registration sites could include social welfare organisations such as Centrelink, or Post Offices in small or remote communities. This would accommodate the homeless, itinerate workers, people who do not have access to a personal computer or a local health service.

In relation to registration of individuals to the PCEHR System, the ANF queries the status of people such as the homeless, refugees, and other individuals who do not currently have a Medicare number or other forms of identifying documentation. This may also be a problem in remote areas of Australia where some Indigenous people are known by more than one name. If the law is silent on these groups of people, or if they are unable to provide the required forms of identification verification, does this mean that they will or won't be able to register onto the PCEHR System?

Q3 What possible barriers are there to the participation of individuals through their authorised representatives?

The ANF agrees that the "legislation would only provide a broad framework to support the participation of individuals through authorised representatives, and be supplemented by administrative arrangements and policy which would provide flexibility to accommodate changing circumstances."

A suggested barrier to consider is the difference in legislation across States/Territories in relation to, for example, guardianship/administration. The ANF seeks clarification as to how this will be accommodated when the individual relocates/moves temporarily interstate.

Q4 What other circumstances might need to be accommodated in the administrative arrangements for minors?

Consideration needs to be given to the situation of multiple parents - that is, through divorce and step-parent scenarios. In this case, it is quite likely that the child moves between parents and thus, in the event of a medical emergency may not be with the parent who is listed on the Medicare card (and the recognised authorised representative for that child).

Q5 What are the possible risks related to the creation and use of a pseudonymous PCEHR?

Possible risks related to the creation and use of a pseudonymous PCEHR, include fragmentation or duplication of healthcare records. There is also the possibility of errors if any future merging of pseudonymous information back into the true identity of the individual.

Q6 Are there other terms and conditions that should apply to healthcare provider organisations in regulating the eligibility of authorised users?

The eligibility criteria on page 18 for an authorised user would appear to cover casual bank or locum staff but not necessarily agency or more itinerate staff. These people would need to provide the healthcare provider organisation with their Healthcare Provider Identifier - Individual (HPI-I) number when signing on for a shift, as their name and matching HPI-I will not be on record at the organisation nor be identifiable in the healthcare provider organisation's local system. Providing their details would mean that when an audit of users of the PCEHR system is undertaken, the HPI-I would be able to be matched to a name of a health professional who has worked in the organisation.

Q7 What are the essential rules and standards with which a nominated healthcare provider should comply in relation to authorising and managing shared health summary?

In relation to shared health summaries and event summaries, the ANF perceives a problem with legislating that "an individual could only nominate one healthcare provider organisation at a time to manage their shared health summary…". This could be problematic in the situation (not at all uncommon) of the individual with, for example, a chronic condition with co-morbidities, who regularly attends appointments with a range of health professionals who all need the same level of access to contribute to the health summary.

Also, there is a risk of the present problem experienced by some general practice nurses of not being able to gain access to patient records for recording given care, being perpetuated and applied more broadly, if legislation states/infers that only one nominated health professional can enter information on the PCEHR event summary.

Q8 What are the essential obligations that should apply to the PCEHR system operator?

- Privacy controls
- 24 hour cover for a helpline for system users
- Authorised user authentication
- Audit capacity of users
- Secure site for use of system

Q9 What are the essential obligations that should be met by repository operators?

- Security of data
- Integration of information
- Interoperability of systems
- Authentication of repository operator staff

Q10 What additional criteria might be applicable to the national repositories?

- Ability for system to store the vast amount of data required
- Ensure speedy access of data by system users
- Security against system 'hackers'
- Robust back-up systems to protect data in the event of system failure

Q11 Are there any other trusted data sources that should be included in the legislation from the outset of the PCEHR system?

A trusted source from the perspective of data required on health professionals for the establishment of their IHI-I is the Australian Health Practitioner Regulation Agency (AHPRA).

Q12 Are there any other essential requirements for portal providers?

Security of any information held, even if temporarily.

Q13 Are you aware of specific examples of information for which intellectual property rights might present a significant barrier to the use of the information in the PCEHR system?

As mentioned previously the ANF is aware that some general practice nurses have experienced difficulty in accessing patient records under current systems, as this is deemed to be the property of the general practitioner. For the purposes of either retrieving information or of recording provision and outcomes of care, we view this practice as having the potential to compromise health care interventions. It is vital that the PCEHR system is not set up to perpetuate negative practices.

Q14 Can you identify any other options for records retention and can you identify any other issues regarding records management that have not been considered in this paper?

Will it be possible for individuals to gain access to, and print off, the information if they desire, when the retention time expiry date is approaching?

Q15 Are there additional access functions for individuals that need to be included in legislation?

Difficult to foresee at this stage. As this is relatively uncharted waters, a period of evaluation of the legislation needs to be built into the implementation process for the PCEHR to which people can direct issues not covered by either the legislation or the accompanying regulations.

Q16 Should any specific restrictions apply to the extent to which an authorised representative can act on behalf of the individual within the PCEHR system?

There will be times when a health professional needs to be able to access the PCEHR system to review notes outside of a time of meeting with the person belonging to that PCEHR. This may be for a pre-appointment review of the health history or during the course of a prolonged process of testing to determine a diagnosis. Legislation and application of penalties should not restrict the justifiable review of an individual's PCEHR.

Q17 Are there any other essential or additional requirements or obligations of a nominated representative that should be supported in the PCEHR legislative framework?

Not that are obvious at this stage.

Q18 Are there any reasons why an individual should not be able to choose a minor as their nominated representative?

No, although probably the age ranges used in other circumstances should sensibly apply here. That is, the issues paper says "Across the health sector, the generally accepted age of competency and decision-making capacity in respect of medical treatment is 14 years."

Q23 What privacy legislation should apply to repository operators?

The same as for other holders of confidential information, but, with additional protections against breaches to the electronic system by "hackers".

Q24 Are there any reasons why clinical information downloaded from the PCEHR system should be required to be handled differently to other information held by a healthcare provider in their local records?

Possibly not, although electronic information can be disseminated much more readily and widely than paper based, and in a speedier time frame.

Q28 Is the size of the penalty (50 penalty units or $5,500) used in the HI Service appropriate for the PCEHR system?

The ANF has concerns that a health professional may in fact be acting in good faith and inadvertently incur the penalty. For example, the health professional may access a person's PCEHR in an emergency situation, and may not be aware/doesn't have time to check that the organisation in which he/she is employed has become unregistered (for some reason).

There needs to be an appeals process so that a health professional, who can show that they acted in good faith, has the opportunity to do so before being hit with a penalty fine.

Q31 If the system operator is an agency and its employees are subject to the Code, would these disciplinary measures be sufficient?

Existing measures cover current practice breaches so there may be no need to have a separate process just because it's an electronic system.

Q32 If the PCEHR system operator is a private sector organisation would additional mechanisms be required?

Different processes may need to be applied if the private sector organisation does not currently adhere to a similar code of conduct to that used within the public service.

Q33 What are your views about the preferred governance structures for the PCEHR system and national e-health elements more broadly?

The ANF contends that nurses, midwives, medical practitioners, allied health professionals and consumers must be members of clinical governance structures for the PCEHR system.

3. Conclusion

Privacy and security are a significant challenge for every health and aged care organisation and a concern for all Australian citizens. People in Australia have an expectation and trust that the use of information in the health environment is secure and that all health professionals will provide the systems and adhere to processes that will protect this information about their health status. It is essential that the legislation, privacy, security mechanisms, secure messaging, governance and quality systems that underpin the PCEHR are explained to everyone in the community. To engender trust and confidence in the system, the PCEHR system must be seen as being safe for health professionals and their clients/patients/residents.

The crux of the legislative framework for the PCEHR system is that it recognise the centrality of the consumer of health or aged care services. Paramount then is the development of laws and regulations which ensure protection of people's privacy in relation to their health data. Of high importance also is a system which is manageable from the perspective of the health professional. Electronic systems should benefit clinical practice and not add administrative burdens.

With a large cohort of members in the health and aged care sectors, the ANF has a genuine interest in the implementation of an electronic environment for managing health and aged care information. The nursing and midwifery professions need the assurance that electronic systems will give them tools to enhance their practice, and therefore the health and well-being of the people for whom they provide care.

The ANF looks forward to continuing to contribute to the work of creating an electronic health information management environment across the health and aged care sectors.