Australian Nursing & Midwifery Federation

Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper

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Lee Thomas
Federal Secretary

Annie Butler
Assistant Federal Secretary

Australian Nursing & Midwifery Federation
PO Box 4239 Kingston ACT 2604
T: 02 6232 6533
F: 02 6232 6610
E: anmfcanberra@anmf.org.au
W: www.anmf.org.au

Introduction

Established in 1924, the Australian Nursing and Midwifery Federation (ANMF) 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 ANMF's core business is the professional, industrial and political representation of its members.

The ANMF represents over 240,000 registered nurses, enrolled nurses, midwives and assistants in nursing nationally. These nurses and midwives are employed in a wide range of enterprises in urban, rural and remote locations, in the public, private and aged care sectors including nursing homes, hospitals, health services, mental health services, schools, universities, the armed forces, statutory authorities, local government, and off-shore territories and industries.

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 professionals, the ANMF has a keen interest in the development of health information management in the electronic environment. We thank the Australian Government, Department of Health for the opportunity to comment on the *Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper.*

The ANMF has supported the development and implementation of the PCEHR system. We have made a significant contribution to the work of the National E-Health Transition Authority (NEHTA) and to the development of the PCEHR system, through funded projects, written submissions and personal representations, including participation on relevant committees. We have made this investment in time and effort because of the benefits to be gained by the community, our members and other health professionals through an information system which delivers timely and consistent communication on a person's health status and history.

General comments:

The ANMF takes this opportunity to revisit issues we have previously identified as barriers to the success of the electronic health record system:

- Lack of investment in infrastructure, software and IT support across the health and aged care sectors;
- Lack of funded scholarships for health professionals to be educated in health informatics to ensure we have the expertise within clinical settings.
- Slow or inadequate implementation of the National Broadband Network (NBN). Access to the internet in some metropolitan areas, rural towns and remote locations remains compromised.
- Insufficient communication, education and engagement with all consumers and health professionals within the country on the electronic health record. As the system is complex, it is essential the communication and education strategy for the proposed changes to the PCEHR system are extensively communicated using plain English.

The nursing and midwifery workforce are highly educated and strategically placed within health. We are the key enablers and drivers for successful implementation and utilisation of the national electronic health record.

Background

The ANMF maintains its position on the importance of the PCEHR system and supports the continued work being done to evolve the system to ensure it improves the availability and quality of health information.

Legislative proposals: PCEHR system and HI Service

The ANMF supports the proposed change in name from PCEHR Act to 'my health record' Act as it is simple and clear.

The inclusion of 'a health-related disability, palliative care or aged service' to the definition of a health service is important and is supported by the ANMF.

Consistency across the 'my health record' Act and privacy Act relating to the definitions of health care and health information is logical.

In relation to expanding 'identifying information', it is important to note that although gaining mobile numbers or e-mail addresses is an easy way to communicate with individuals, not all individuals have access to SMS or email. There would need to be alternate options for these individuals.

Further clarification is required to outline the information that would be provided to an individual when notifying them that their record has been accessed, for example, how the consumer understands and consents to which health professionals may access their health record. In particular, in the community health setting or an acute hospital setting many health professionals may access the record legitimately, however the consumer may receive a number of alerts that their record has been accessed and not understand the reasons for this access.

It is unclear whether the notification will be just an alert or whether it will provide all relevant details about the access including date, health provider number and health provider organisation. If an individual is concerned about the access and would like to investigate it further or even report it, what processes are there for accessing their record online to progress their concern; and, what organisation is tasked with this responsibility?

Governance

It is reasonable to establish a separate entity to be responsible for all national eHealth systems, however detail regarding the establishment and transition of these arrangements is required to provide further comment.

In relation to the proposed Australian Commission for Electronic Health (ACeH) Board, we believe it is essential that a nurse/midwife with the required expertise is a member of this Board and that nurses and midwives are represented at the advisory committee level.

Participation

The ANMF has long advocated for an opt-out system to increase the uptake and effectiveness of the system. Although it may be confusing for individuals to have two systems in place for a period of time, one being the trial area where the system is opt-out and the ongoing system where individuals are required to opt -in, it is reasonable to implement this important change in stages. This will enable any barriers to be managed and adjusted on a smaller scale. It would be essential that this potential confusion around the two processes is considered and addressed in the communication strategy.

The communication strategy must include clear explanation and education for the consumer and all health professionals. This should include the legislative arrangements that authorise the registration and uploading of records by health care provider organisations and individual health practitioners. The legislation discussion paper proposes that the communication strategy will circumvent the need for consent, as is used in the opt-in system-this key point must be understood by all users of the PCEHR.

The ANMF supports the ability for individuals to opt-out at any time of the trial and defer involvement to register at a later date if required. This would be an essential aspect of an opt-out participation model, as part of national implementation.

There may be circumstances where a healthcare provider is not able to upload a health assessment, comprehensive assessment, mental health plan, medication review report or chronic disease plan apart from where an individual does not have a PCEHR identifier or if the individual requested the document not to be uploaded. These include:

- Where a healthcare provider does not have the infrastructure within their service to upload a document to the PCEHR system.
- Where the consumer has applied specific controls to prevent health professionals accessing their health record.
- It is noted in the document that, in opt-out trials, *"Healthcare provider organisations, contracted service providers, repository operators and portal operators will continue to participate on an opt-in basis"*. Therefore, any health care provider working in an organisation that has chosen not to opt-in, will not be able to upload relevant documentation.

In relation to notification to the consumer of PCEHR access, as we have already identified, clarification is required to identify the information that will be provided in the alert and the process for an alert to be investigated. The ANMF supports the addition of an access alert system but is mindful that this will create another layer and could be significantly resource intensive.

Handling by AHPRA

It is reasonable to link healthcare identifiers to the data held by AHPRA, for regulated health practitioners. This will provide an efficient way for all health practitioners to be provided a healthcare identifier. It will also reduce any potential miscommunication between AHPRA and the PCEHR administrators. It is however questionable as to how AHPRA would be able to manage this within their current data system and who would fund the implementation and ongoing maintenance of these processes. As AHPRA is funded by health practitioner registration fees, it would be inappropriate for health practitioners fees to fund this part of the PCEHR system.

Penalties for misuse of information

Nurses and midwives understand confidentiality as it is an essential principle underpinning professional nursing and midwifery practice standards. The ANMF supports the notion of criminal penalties where an individual is found guilty of misusing information gained in the course of their therapeutic relationship with people in their care as a consequence of accessing a PCEHR system.

The context of how any inappropriate access occurred needs to be investigated. We consider it is essential that health professionals have access to appeal in these situations.

If found guilty, appropriate penalties within each jurisdiction needs to be considered and/or notification to the relevant health practitioner Board, where the person involved is a regulated health practitioner. Misuse by people with access who are not regulated, should also be referred to the appropriate health service authority and/or health complaints commission in each jurisdiction.

Next Steps

As the ANMF has previously identified, we consider nurses and midwives are essential in the roll out and success of any proposed changes to the PCEHR system, at all levels. In closing, we look forward to ongoing participation in the progress of the PCEHR system.