Response to Department of Health and Ageing on draft Terms and Conditions for the Personally Controlled Electronic Health Records (PCEHR) system registration

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PCEHR System Registration Terms and Conditions

As the professional and industrial organisation representing over 215,000 nurses, midwives and assistants in nursing, the Australian Nursing Federation (ANF) appreciates inclusion in initial and targeted consultation on the draft Terms and Conditions for the Personally Controlled Electronic Health Record (PCEHR) system registration by healthcare providers. Further to participation in the consultation forum hosted by the Department of Health and Ageing on 3 April 2012, the ANF provides additional written feedback. The response to follow uses the questions posed by the Department of Health and Ageing in the email letter of invitation to the ANF dated 26 March 2012.

Question 1.
Do you understand the terms and conditions? If not is it because of the words used; length of document; complexity of ideas; lay out of information; other (please specify)?

Feedback:
The email letter to the ANF (26 March 2012) states

*In order to make the registration process simple and streamlined, we are keen to ensure that the terms and conditions presented at the time of registration are easy to understand and cover key aspects of the system operation.*

The draft Terms and Conditions document is not easy to understand in its current form, it has strong negative and punitive overtones, and is needlessly complex. In addition, assumptions are made that health professionals do not understand their legal responsibilities and accountabilities within the health care environment. As such the document is most unwelcoming and would be unlikely to attract healthcare providers to register to participate in the PCEHR.

The ANF has been one of the organisations which has fully supported the introduction of a PCEHR from earliest days of discussion on the capabilities of e-health. While it is acknowledged that the consequences of breaching any contract need to be explicit to the ‘signer/s’ this should not overshadow the positive purposes of the agreement between two parties. The ANF would not want the PCEHR system to founder at the stage of sign-on by healthcare providers because the contract acts as a deterrent to doing so. The language needs to be that of a co-operative partnership and not unnecessarily punitive.

We were advised in the 3 April 2012 consultation forum that the Terms and Conditions are contained within a ‘Participation Agreement’ document. It would be useful, for the sake of having a comprehensive view of what will be given to healthcare providers, that stakeholders be able to review the document in its entirety. Also, it should be stated quite clearly at the head/start of this document that it sets out the conditions of agreement between the Healthcare provider and the PCEHR System Operator.

The introductory commentary needs to be reworded to present a positive purpose statement for the contract between the System Operator and the Healthcare Provider. For example the opening statement could be softened just by deleting words like “imposed” and “must agree to be bound by” to words like “required by” to “form an agreement with”. Health care organisations deal with a plethora of sensitive issues and data (for example, mortality and morbidity) and the agreement on the
PCEHR should not be any more or less onerous than conditions applying to all other health care business undertaken. The document in its current form is overly prescriptive in view of the fact that health professionals, in the most part, act in good faith, in the course of their daily activities.

The essence of the first box is really contained in the section “By accepting the Conditions you warrant us that: etc...” These points need to come quite close to the start of this section as it summarises the expectations of the healthcare provider in the agreement between the two parties.

Section 6 is unsettling from two counts. Firstly, as it is written now, the Clause appears to absolve the System Operator of all responsibility in relation to loss of data. Secondly, the inclusion of some of the clauses (for example 6.3) referring to clinical content is redundant from the point of view that all regulated health professionals (such as nurses and midwives) are governed by a professional practice framework. The framework includes standards for practice, Codes of Professional Conduct and Ethics, and maintenance of competence requirements. The regulated health professional takes responsibility and accountability for their own actions in clinical decision making and documentation of same, and any issues arising from this not able to be dealt with at the local level are risk managed through regulatory processes. The point being made is that there doesn’t need to be a clause about the responsibility or otherwise of the System Operator in terms of clinical content of the records.

With regard to Section 7, this clause appears to be unnecessarily heavy handed. Health professionals are dealing on a daily basis with health records of a sensitive nature and have a full appreciation of the need for ensuring confidentiality and security of data handling and storage. The ANF agrees with the point made in the consultation forum that where a complaint is made about the management of clinical information there already exist legislative powers to institute investigative mechanisms – the Office of the Australian Information Commissioner/state or territory equivalents. This negates the need for the System Operator to establish a duplicate process.

**Question 2.**
After reading the terms and conditions, do you think there are any further questions health care professionals might have?

**Feedback:**
Links to documents referred to in the Terms and Conditions would be beneficial – for example:

- the *Personally Controlled Electronic Health Records Act 2012*, as well as associated Rules and Regulations,
- *Copyright Act 1968*.

**Section 1:** The use of the word ‘may’ in Clause 1 (1a and 1b) is problematic. It suggests an excuse for incorrect, inefficient use of or, lack of access to the PCEHR system. Consumers and providers of healthcare (including health professionals) need to have the confidence in the system that the record will be available and be able to be used.

**Section 3:** The System Security Requirements refers to the Rules – the Security section in the Rules is confined to audit trails.
Healthcare providers will be curious as to the definition of the term ‘reasonable action’ in relation to their security measures. In particular, small business operators of health care services, will be relying on Information Technology support services for the maintenance of security over their current hardware and clinical software programs. Will these measures be considered ‘reasonable action’ in relation to the PCEHR system?

In signing on to systems security at their end, healthcare providers will want to see evidence of security mechanisms established by the Systems Operator on the centrally held PCEHR database.

In relation to 3.6, there will need to be a clear and easy method for undertaking notification of security breaches, and assurance of prompt response and feedback in dealing with the matter.

Section 5: Health care professionals will want to know what processes lie behind the changing of conditions ‘from time to time, on our own initiative or at your request’. That is, will there be an evidence base required before changes will be considered and will there be agreement to the changes? The present wording does not give assurance of mutual consent to a change in conditions.

Question 3.

By agreeing to the terms and conditions, your members would be placing themselves under certain obligations with respect to using the PCEHR system. Are there any practical reasons as to why you think that your members would not be capable of carrying out those obligations in a real life setting?

Feedback:

Some issues covered in above commentary.

Section 8: Intellectual Property Rights.

There is an expectation of all health professionals to review their practice and discuss case studies (de-identified) with colleagues. This is seen as a learning tool as they seek clarification on aspects of cases including care given, goals and outcomes of care (prospective and retrospective), and look for evidence of best practice. In addition, health professionals are strongly encouraged to share learnings in publications and conferences and other forums; as well as to engage in research to add to the body of knowledge informing their practice. The current wording on intellectual property rights in Section 8 would appear to preclude any use of clinical information by health professionals for the purposes outlined as current practice.

The ANF urges that this section be reworded to align with what currently applies to intellectual property rights to circumvent stifling clinical review, learning and research. The draft obligations would mean clinical practice and outcomes of consumer care would be severely compromised.

Section 9: Moral Rights. This section is incredibly prescriptive and has the potential in practical terms to severely restrict the practice of health professionals. There are negative implications for the use of materials from case studies (which will be material posted to PCEHR) for the purposes of teaching of health professional students or for continuing professional development. It is unclear as to what constitutes ‘genuine written consent’. Health professionals are well aware of their moral, legal and ethical responsibilities in the healthcare environment. The intimidating language in this section is therefore perceived by the ANF to be unjustified.
Question 4.
Is there anything else that you think should be included in the terms and conditions?

Feedback:

The statement is made in the introductory section that: *You understand that your registration may be suspended or cancelled if the System Operator is satisfied that you have contravened the Conditions*. The ANF is concerned that there is not an accompanying statement on a right of appeal by the health provider who has signed the agreement. Procedures of natural justice would dictate that such a process be included in the agreement.

Concluding comment:

The ANF has undertaken projects on behalf of the Department of Health and Ageing and so is familiar with usual language and expectations of contracts/agreements under which that work has occurred. The language and expectations outlined in the draft Terms and Conditions for the PCEHR system registration is unnecessarily prescriptive, and, appears based on an assumption that health professionals do not understand their responsibilities to consumers of health care services.

As stated previously the ANF has been a long time supporter of the move to an e-health environment. We do not want the implementation of the PCEHR to be sabotaged by a prescriptive agreement which acts as a deterrent to participation in the system.

Whilst it is not within the remit of this particular process, the ANF wishes to record that we are not happy with the inconsistencies inherent in the recent announcement that General Practitioners would be eligible to claim $101 each time they register a person to the PCEHR system. Our concern is the inequity issue this raises amongst health professionals in that this benefit has not been afforded to Nurse Practitioners or Eligible Midwives, who also can make claims under the Medicare Benefits Schedule. This exclusion places a potential barrier to the implementation of the PCEHR system.

It is imperative that we remember and remain true to the original intent of establishing a PCEHR: that is, to gain for consumers more control over their own health record and reduce the need for having to endlessly repeat their health history to each health professional involved in their care; and, to enable more timely access for health professionals to a person’s health record.