

Ms Melanie Goldwater
PCEHR Feedback
Department of Health and Ageing

31 May 2011

Dear Ms Goldwater

Re: NSW Office of the Privacy Commissioner's submission on the
Draft Concept of Operations: Relating to the introduction of a personally
controlled electronic health record (PCEHR) system

Thank you for the opportunity to make comment on the Australian Government's release of the Concept of Operations.

I note that my Office made comment at earlier stages of the development of the e-health records scheme. One of our earlier concerns was an apparent preference for establishing an "opt-out" system, which would have resulted in involuntary participation into the scheme by many in the community.

I am of the view that an "opt-out" system will unreasonably interfere with the privacy choices of individuals, as they will lose control of who among health practitioners will-

- Have access to their health information, and
- Have authority to upload objective data and subjective opinion about them.

In my view being able to make a conscious choice regarding these two issues maintains a longstanding public policy that enables the community to have effective control of the management of their health.

Recent discussion in the print media (such as the article "*Fight over medical files,*" Sunday Telegraph, 29 May 2011, page 32, published in Sydney) indicates that a concern by some health practitioners is the potential that e-health records might be incomplete, resulting in them using unreliable data and thus being open to claims for damages.

This perceived risk exists since the inception of professional health services. Access to a nationwide verifiable patient record has not been a feature of health service delivery to date and I do not consider that the introduction of an e-health records scheme should be relied on to diminish a health practitioner's own responsibility to provide good care.

In this regard I commend the overall “opt-in” policy setting in the Concept of Operations. In my view it has the potential to provide an additional level of flexible data transfer to assist individuals receive quality care without compromising an individual’s privacy rights.

After reviewing the Concept of Operations I have some concerns about some of its provisions as follows:

1. Personal control

At page 6 the following appears:

Choose which information is published to and accessible through their PCEHR: Individuals may request healthcare providers to not send information to their PCEHR.

There is a comment to the same effect at page 20.

I consider that the scheme’s “opt-in” policy setting will be undermined if health practitioners were granted the decision making power as to what is uploaded onto a registered individual’s e-health record unless and until that individual requests them “to not send information.” In my view this will have the potential of rendering registered individuals effectively captive to the subjective choices of health practitioners.

2. Access by health practitioners

At page 7 the Concept of Operations discusses access to the PCEHR system by health practitioners. I am concerned that it does not expressly provide for a generally authorised user of the system to require an individual’s permission to locate the individual’s e-health record, access it and upload information into it.

If my reading of that section is correct, I consider that the “opt-in” policy setting of the scheme and one’s general privacy rights would be defeated by allowing health practitioners to access and use an individual’s records in circumstances where the individual might not wish them to do so.

3. Oversight

At pages 8, 12, 14, 25, 49 and 51 the Concept of Operations discusses issues about oversight, complaints and sanctions.

A reading of those sections suggests that there is an emphasis on the concept of “sanctions,” which may indicate that the scheme will provide mechanisms only for the punishment of wrongdoers at the instigation of a government authority.

Firstly, I am concerned that the Concept of Operations does not identify any of the “Service” areas of the system that will be given specific functionality to operate the oversight and complaints processes that the system envisages. I consider that an effective complaints management system should clearly allocate operational

responsibility to a particular division, or “area,” so that users can be immediately informed as to who they should contact for their complaint and who will have responsibility to deal with it.

Secondly, because misuse of the system may infringe upon some fundamental rights such as privacy, I consider that its operations document should include information about -

- the complaints system that will operate within the scheme, and
- other rights available to individuals to obtain remedies outside the scheme.

I consider that an effective complaints system should include the following component parts:

- Mechanisms of administrative complaint handling and resolution, and
- Enforceable civil remedies at the instigation of individuals, and
- “Sanctions” against wrongdoers at the instigation of a government authority, whether for civil or criminal penalties.

In my view a system dealing with potentially serious infringements of one’s rights should not only put a government authority in the driving seat of enforcement, but it should also make clear provision for aggrieved persons to commence legal actions where they are in control of their case and where they stand to directly benefit from any outcomes. I consider that the Concept of Operations should clearly refer to the civil remedies under state laws, such as state privacy legislation, that should continue to operate.

Thank you again for the opportunity to make submissions on the Concept of Operations and I trust my comments will be of assistance.

Yours sincerely

John McAteer
Acting Privacy Commissioner
Information and Privacy Commission