

Submission to the
Senate Community Affairs Committee Inquiry into the
Personally Controlled Electronic Health Records Bill 2011

Dr Rod Phillips
Chairman, Vascular Anomalies Committee,
Royal Children's Hospital

January 2012

Introduction

I have been monitoring the PCEHR legislation over the past two years and have provided feedback at every stage. In general, the legislation is very good. If handled correctly, it may lead to a much greater involvement of consumers in their health care and a consequent improvement in patient centred care and patient safety. This will not happen unless consumers trust the legislation. I wish to raise five areas of concern where trust may be lacking.

1. The Audit Trail

It is essential that consumers can identify everyone who accesses their record. Although the draft Bill appears to say this, the wording is not precise. I am concerned that consumers will only see episodes of access by Health Care Providers, not access by other employees such as IT staff. The audit trail must include all access by PCEHR employees and other government employees. This needs to be specified in the legislation.

Recommendation: The Bill needs to specify that consumers will have access to the complete audit trail of their PCEHR.

Recommendation: The Bill needs to specify that consumers can still access the audit trail of their PCEHR even after deactivation. This is essential as all records in their PCEHR will be retained and hence could be inappropriately accessed after deactivation or suspension.

2. Emergency Access

Consumers should have the right to deny emergency access to parts of their PCEHR.

The Bill allows any health care provider to access any part of a consumer's PCEHR in an emergency, *even if the consumer has explicitly stated that they forbid access to those parts of their record*. This is inconsistent with Australian medical law under which medical care cannot be forced on any competent adult. The wish of a person who states in advance that they will not receive blood products if they are dying is recognized by law. This situation is analogous with a person who states they do not want certain information in their PCEHR to be available even in an emergency.

It would be a legal absurdity to allow individuals to refuse emergency treatment but not allow them to refuse emergency access to parts of their PCEHR that they want to keep private. For example, a 55 year old woman attending with a heart attack may absolutely want to keep hidden details of an abortion 30 years ago, and she should have the right to do this.

Recommendation: a consumer should be able to explicitly forbidden emergency access to parts of their PCEHR”

3. Deletion of part or all of a PCEHR should be permitted

Adults can choose to start a PCEHR. However, they cannot choose to delete it once formed. They can only deactivate it. This leaves their PCEHR still intact and available to many to view – e.g. IT staff, departmental staff.

This is based on a misunderstanding. It is incorrect to consider PCEHR data as analogous to data held by Health Care Providers. No original document is stored there. All documents are just copies of source documentation held by Health Care Providers or others. PCEHR records should not be treated as though they are original medical records that need to be kept for 7 years, or longer. All data that is in a PCEHR still exists even if the PCEHR is deleted. There is no medical or legal reason why consumers should not be able to delete their PCEHR, or parts of it.

Adults should have the right to permanently delete part or all of their PCEHR. This would obviously need to be accompanied by warnings and a cooling off period. An example of this in practice might be someone who authorises their hospital to upload data to their PCEHR, but later realises this data includes an abortion they had 30 years earlier. The current suggestion that they can block some access to that document is insufficient. The consumer needs to be able to say “Sorry, my mistake – I did not want that document there at all.”

If adults are not able to delete any part of their PCEHR, this must be explicitly declared before consumers sign up.

It is worth noting that groups such as the Consumer Health Forum are advocating an Opt-Out model rather than an Opt-In model in order to increase the rate of involvement in the PCEHR. Consumers are much more likely to Opt-In if they are given genuine choice that includes recognizing they have made a mistake about adding certain data. Consumer uptake is certain to be more rapid if they are offered the ability to delete parts or all of their PCEHR.

Recommendation: That consumers should, with appropriate safeguards, be able to permanently delete any of the documents in their PCEHR. This will increase consumer acceptance and uptake.

4. Issues relating to children – the ability to delete copies of some data

The inability to delete is an even bigger problem for children. Although the PCEHR system is portrayed as voluntary, many children will have a PCEHR created for them by others. Data will be recorded that may be embarrassing and irrelevant to their health care as an adult. Examples include: photographs of genital lesions, details of genital abnormalities or operations, and psychiatric assessments (often recorded in hospital data as performed on the child as a means to get funding for widespread family issues and support).

In order to protect their rights, children need to be able to make informed decisions about consent when they as adults take control of their PCEHR. This can only be achieved if they have the functionality (at least once in their adult life) to permanently delete specific entries or their entire PCEHR. Thus a new adult may choose to remove all mention of a series of genital operations done in the first two years of life. Another young adult may elect to delete their record, declaring that they do not want a PCEHR. Later, they might choose for themselves to have one, but they need to be able to make this choice. They are then in a position to determine what goes into their record.

Clearly, deletion is a much bigger step than cancellation and it would need to be guarded with adequate warnings about the irreversible nature of the deletion. It could also be protected by making the deletion not take effect for a specified period to allow for a person to change their mind. The option to delete could be only available for a specified period after reaching adulthood if it is deemed inappropriate that other adults can also delete items.

Recommendation: That, even if adults are not granted the general right to delete from their PCEHR, when a child becomes an adult they should have at least one opportunity, with appropriate safeguards, to permanently delete any of the documents in their PCEHR. This will increase consumer acceptance and uptake.

By Dr Rod Phillips, Chairman, Vascular Anomalies Committee, Royal Children’s Hospital, Melbourne