

PCEHR – consumer aspirations and issues

Most Australian's believe that there should be a system of shared electronic health records in Australia. There is an underlying assumption that they could help improve healthcare, but many consumers believe there are some important issues to be addressed, most notably around their usefulness and around privacy and access control. This paper tries to postulate some consumers' aspirations as well as their concerns related to the proposed national system of Personally Controlled Electronic Health Records (PCEHR) announced in the May 2010 Commonwealth health budget.

1 Consumers' Aspirations

1.1 EHR access for healthcare providers

The PCEHR should aim to improve healthcare. This is best achieved through giving healthcare providers appropriate, but easy access to the EHR, and should include:-

- integration with their clinical systems
- being an accurate and comprehensive record of – medication history; adverse reactions and allergies; history of problems, history of interventions; history of tests; history of test results; immunisation history; referrals and discharge summaries; special alerts (e.g. epileptic, pacemaker, unstable diabetic, haemophiliac)

1.2 EHR relevant to each consumer's health conditions

Consumers vary in their requirements and expectations. We need a system that supports considerable diversity, including:-

- need for care planning, particularly chronic conditions
- need for appointments schedule/scheduling
- need for tailored clinical content
- coupling to online knowledgebases
- special authorisation and access controls for specific conditions

1.3 EHR relevant to each consumer's wishes and ability

The access to the PCEHR by consumers needs take into account the diversity of consumer's wishes and abilities:-

- willingness to access online information
- willingness to update online information
- ability to access or update online information
- willingness and ability to control access for others – carers, healthcare providers, researchers
- attitudes to privacy and confidentiality
- support for offline access – via download, or printing when visiting healthcare provider

1.4 Support for processing of information across healthcare providers

Current systems are silos belonging to each healthcare provider or provider organisation. We need a system that can transcend these silos and give longitudinal, i.e. lifetime information via:

- aggregation of information
- support for trend processing – e.g. *HbA1c levels; Prostate Specific Antigen* markers
- support for research
- support for location information – where in the world a condition or treatment occurred
- special forms of aggregation – e.g. *accumulated radiation dose from CT scans*

2 Consumers' Issues

2.1 Trust

The usefulness of a PCEHR system is critically dependent on the trust placed in the system and system management by its participants, be they consumers, healthcare providers, researchers, funders. Examples of trust include:

- trust in the accuracy of information
- trust in the completeness of information
- trust in the currency of information
- trust that there are/will be appropriate privacy and security safeguards
- trust that the system will be used efficiently and effectively
- trust that the system will continue to evolve and improve
- trust that perceived deficiencies, inaccuracies, etc. will be addressed
- trust that information will not be misused
- trust in the reliability of access – can consumers and providers access when and where they need to?

Trust is hard to create, but easy to destroy. It is critical that stakeholders' issues be addressed from the outset, and continue to be addressed throughout the life of the PCEHR.

2.2 Governance

Up until now, the track record on governance arrangements for the PCEHR and e-health more broadly is very poor. Consumers want and expect all stakeholders to be engaged in a collaborative process that determines the best governance and management regime for each aspect and phase of e-health developments. Consumers want any PCEHR development to be part of a well-articulated and well-accepted national e-health framework.

2.3 Openness of process

Up until now, the track record on openness of process is abysmal, particularly by NEHTA.

- Why has the PCEHR business case not been made public?
- Why has no concept of operations for the PCEHR been published?
- What role does/should NEHTA play?
- What role does/should DoHA play?
- What is the best governance framework for e-health and for the PCEHR?
- Why is the current conceptualisation of the PCEHR so vague?
- Why is there such poor financial accountability?
- Why is there no linking of the current process to the lessons learned from *HealthConnect*?

2.4 Information privacy, security, confidentiality

Strict controls of the PCEHR are required to prevent unauthorised access by government agents, insurance companies, employers, etc. Yet these controls should not inhibit the “legitimate” access to information as determined by agreement between consumers and providers of the information.

2.5 Support the diversity of consumer conditions and consumer accessibility constraints

- Different conditions require different information to be stored in the PCEHR. A “standard” set of data will disenfranchise those with “non-standard” conditions.
- Some consumers want to be very active in managing their clinical information, others may not be.
- There is often a mismatch between clinicians' levels of trust in their patients' abilities to manage

information and their patients' actual abilities.

- Some consumers are better able to manage their medical information than their healthcare providers.
- Some consumers will have and will continue to have considerable difficulty accessing and or controlling access to a PCEHR (e.g no internet connection, poor computer skills, mental impairment).

2.6 Mechanisms to make information available for research without compromising patient confidentiality

Many, but not all consumers, are prepared and willing to provide information for medical research. Two mechanisms that could be managed under the PCEHR authorisation infrastructure are:-

- consent to use de-identified data
- establishment of a registry for donated information. Many Australians are prepared to donate organs or tissues for other individuals or for research. A dedicated facility could be established for health information.