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 that there are some important issues to be addressed, most notably around their usefulness and around privacy and access control. The following is an attempt to capture 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 PCEHR Content and Functionality

The primary aim of the PCEHR must be to improve the healthcare of individual patients that choose to participate in the scheme. Consumers' requirements and expectations vary, so the system must support considerable diversity and be relevant to individuals conditions and needs. There is a particular need to support those consumers with chronic conditions and complex conditions (co-morbidities), where better sharing of information can reap substantial benefits.

Categories of content that might reasonably be expected to be supported include:-

- data relevant to emergency treatment
- important encounters
- important episodes
- 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)

Additional functions that should be supported by the PCEHR system infrastructure:-

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

1.2 PCEHR access for healthcare providers

The PCEHR should aim to improve healthcare. This is best achieved through giving healthcare providers appropriate, controlled, but easy access to the EHR, through integration with their clinical systems. To be effective for clinicians, data quality is essential, and systems should ensure:-

- accuracy
- precision
- timeliness
- comprehensiveness

There is also a need to ensure adequate accessibility for rural and remote providers, who may currently only have narrowband connections.

1.3   Facilitation of EHR Access by Healthcare Providers

For patients that want it, the PCEHR should facilitate controlled and as-needed linkage to EHR data stored in healthcare provider's databases, in order for each relevant healthcare provider to view comprehensive longitudinal, i.e. lifetime, information for that patient. Examples include:-

- Capability of individual healthcare providers to gain access to all relevant information
- Support for trend processing – e.g. HbA1c levels; Prostate-Specific Antigen markers
- Controlled and protected access 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

1.4   PCEHR Access for Patients

Each consumers' own access to their PCEHR needs to reflect the diversity of consumers' wishes and abilities in such areas as willingness and capability to use online facilities, and attitudes to privacy and confidentiality.

Consumer access to the PCEHR:

- online, by themselves
- online, by agents such as carers and healthcare providers
- off-line, via download, or printing when visiting a healthcare provider
- full access, where appropriate mediated by a professional with appropriate qualifications

Consumer updating of the PCEHR:

- online, by themselves
- online, by agents such as carers and healthcare providers
- future support for online upload from home monitoring devices
- ability to have data amended or to have additional information associated with entries

1.5   Support for Consumers

The PCEHR must help consumers who want to be active in the management of their own health, particularly those with chronic conditions, in order to fill gaps in their care that currently make healthcare suboptimal for consumers.

- Help in the reduction of the incidence of unnecessary tests
- Save having to repeat basic information at each first encounter with a new provider
- Assistance to patients in weighing up the pros and cons of treatments being offered or advised, through the provision of links to appropriate information, such as:
    - medication instructions
    - interpretation of results
    - known side-effects of tests and treatments
    - typical outcomes of treatments
- Provision of links to assist in the assessment of costs, including out-of-pocket costs for diagnostic tests and treatments

1.6   Support for Diverse Categories of Consumers

The interests of consumers, and their needs from the PCEHR and eHealth more generally, varies considerably depending on the particular category or categories that the individual patient belongs to.

The highest priority in the PCEHR's design should focus on patients with:

- chronic conditions

- complex conditions (comorbidities)

- high-dependency aged

- the aged more generally

Different considerations arise in respect of the following categories:

- acute conditions

- remote patients (and in many cases also rural patients)

- itinerants (which encompasses 'grey nomads', 'travelling salesmen', aboriginals living a traditional lifestyle, 'fruit-pickers', vagrants and 'street kids')

- families

- adolescents (i.e. people in transition from childhood to adulthood)

- those with culturally-sensitive conditions (which encompasses sexually-transmitted diseases, gynaecological conditions, and mental health; conditions of especial concern within particular ethnic, lingual and religious cultures; conditions of especial concern to particular individuals (whether rationally or otherwise) e.g. diabetes, leprosy, glandular fever, etc.)

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 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.

2.3 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.
- Consumers vary considerably in their health literacy. Will the PCEHR cater for this diversity?
- 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).
- How will child access be handled? Will parents control young childrens' access?
- How will children's private interests be secure from parents? Of particular concern to teenagers.
- How can the PCEHR best serve the interests of those not computer literate and those with poor accessibility options. We don't wish to exacerbate the digital divide. This particularly applies to the very ill and the elderly – those for whom a PCEHR should particularly aim to help.

2.4   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 similar, dedicated facility could be established for health information, provided that it supports an acceptable and workable regime of controls on how information is to be shared with research organisations.

2.5   Governance

Up until now, the track record on governance arrangements for the PCEHR and e-health more broadly has been to closed to the broader community, particularly consumers. Consumers want and expect 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. Governance partners should include representatives of consumers, government, healthcare providers, and the health IT industry.

Consumers want any PCEHR development to be part of a well-articulated and well-accepted national e-health framework. Consumers are concerned to ensure that the all e-health initiatives are founded on appropriate standards, present value for money, build on the lessons learned from local and overseas endeavours, are well managed, and are evaluated for their ability to improve the healthcare provided to all Australians.