

Personal electronic health records: the start of a journey

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SUMMARY

Technology is poised to drive dramatic change in the way healthcare is delivered. Many countries are using health information technologies to improve the safety of healthcare and reduce costs.

There is an evolving capability for health information to be accessed and exchanged between healthcare providers in real time.

Shared electronic health records are increasingly seen as having a key role in facilitating access to and exchange of data, promoting engagement with self-management, and supporting continuity of care.

Sharing electronic health records with consumers supports the move to more informed patients becoming active partners in their own health care.

Consumers can access their own health information, contribute to their health record and interact more effectively and efficiently with the health system.

Introduction

In 2009, the National Health and Hospitals Reform Commission recommended the introduction of a person-controlled electronic health record for each

Australian as one of the most important systemic opportunities to improve the quality, safety and efficiency of health care.¹ It was proposed that the electronic health record would provide a minimum level of health information that would be available nationally. Access to this information would be controlled by the individual.¹ This recommendation led to the Australian Government funding \$467 million in 2010 to begin the development of the personally controlled electronic health record (PCEHR) system.

The start of the PCEHR

The PCEHR was launched in July 2012. From then people could register to participate in the system which is currently viewed through a government-run web-based portal. The key features of the PCEHR are shown in Table 1.

The National e-Health Transition Authority has provided the essential foundations for the PCEHR. These include healthcare identifiers (for individuals, providers and provider organisations), secure messaging, the national security and access framework and national clinical terminologies (for example Australian Medicines Terminology).

The PCEHR is 'opt in' for both consumers and health professionals. With agreement, a shared health summary can be created by a nominated healthcare professional. This will initially include a brief medical history (as a problem list), current medicines, immunisations, allergies and adverse reactions.

Consumers will be able to join or withdraw from the system at any time. If they opt in, they can enter their own information into the consumer area of the portal. This could include details of medicines they are currently taking including prescribed, complementary or over-the-counter medicines, and allergies.

Consumers cannot edit information created by others, but they can choose the documents to be shared. This means that people can hide documents which contain sensitive information or healthcare events that they do not want recorded and choose which healthcare organisations access their record.

In contrast to some other systems, the Australian PCEHR is not a shared electronic health record system. Primary records are still maintained and stored locally – general practices, hospitals and other organisations will continue to maintain and

From the Editor



The introduction of paediatric pneumococcal vaccine has seen a dramatic decline in invasive pneumococcal disease. Clayton Chiu and Peter McIntyre update us on this important immunisation for children and the elderly.

Many elderly patients take drugs to lower cholesterol, but they have an increasing risk of adverse effects, according to Sarah Hilmer and Danijela Gnjidic. Some

of these adverse effects are due to drug interactions and the article by Catherine Lucas and Jennifer Martin also looks at interactions, specifically those associated with cigarette smoking.

The *Australian Prescriber* article on calcium supplements provoked a lot of interest. The letters section of the journal has therefore been expanded to enable readers to consider the resulting correspondence.

use their own records as the primary data source. The PCEHR is therefore a collection of summary documents and data uploaded from a variety of primary sources at different times (see Table 1). It will not always be clear if the information in the PCEHR is up to date. Reconciling information from different sources may be time-consuming when there are multiple summaries.

Uptake and use

As expected, uptake of the PCEHR has been slow – in the first nine months, approximately 109 000 consumers registered to use it. The original target of 500 000 consumers in the first full year of operation will be difficult to reach. The complexity of the registration process has been a major barrier. There are models being explored to improve consumer registration as it has been recognised that the existing systems are a barrier to uptake. However, there are few drivers for use by either consumers or health professionals when there is little clinical content to see.

Quality use of medicines

Prescribed or ceased medicines will be contained in a variety of documents including the shared health

summary, discharge summaries and event summaries. Consumers and providers will also be able to view medicines that have been prescribed and dispensed electronically by participating health practitioners from mid-2013. Bringing this information together into a single, consolidated, current medicines list is desirable but unlikely to be implemented in the short term. It will be important for users to understand that a particular view of medicines information within the PCEHR may be incomplete. Australia’s ‘Guiding principles to achieve continuity in medication management’ are particularly pertinent, outlining a partnership approach in which expertise and responsibility is shared among healthcare providers and consumers, for the consumer’s well-being.²

International experiences with electronic health record systems

The development and implementation of large scale, shared electronic health records is complex and expensive. It is difficult to find examples where such systems have been delivered on time, on budget and have satisfied the needs of both funders and users. The lessons learned from the implementation of systems in other countries are important as they

Table 1 Key features of the Australian personally controlled electronic health record (PCEHR)

Participation model	<ul style="list-style-type: none"> Opt-in for consumers Opt-in for health professionals and healthcare organisations Healthcare organisations must register for the PCEHR Healthcare organisations need to use compliant software to upload information Consumers can register for the system online, by phone, at participating Medicare offices, through participating general practices or by mail Consumers can choose the information to be shared, which healthcare events are stored on the system, which healthcare organisations access their record, and can withdraw from the system In certain life-threatening situations, where patients are incapable of giving consent, emergency access protocols can be used to search for and then view an ehealth record
Information contributed by healthcare professionals	<ul style="list-style-type: none"> Shared health summaries containing medical history, allergies and adverse reactions, immunisations and medicines Event summaries can be created and uploaded by authorised healthcare professionals and may contain details about the attending healthcare professional or organisation, reasons for the patient’s visit, diagnoses, results, treatments and observations Discharge summaries are created on a patient’s discharge from hospital and may contain details about reasons for the visit, diagnoses, tests ordered and their results, interventions, drugs and recommendations for further treatments Specialist letters which will include details about the referring doctor, regular providers, interventions and treatments Medicare data including child immunisation data, organ donor register data, benefits claimed and subsidised drugs dispensed Until recently, the intention was to have pathology results available from some private laboratories in July 2013. This now appears unlikely. It is not known when pathology and radiology results will be incorporated into the PCEHR.
Information contributed by consumers	<ul style="list-style-type: none"> Allergies and medicines (this information will be clearly shown as patient-provided information) Consumer-entered notes e.g. diet, exercise and potentially results like blood glucose and blood pressure (consumer-entered notes will not be accessible to healthcare professionals)
Incentives for health professionals and organisations to participate	<ul style="list-style-type: none"> An ehealth practice incentive payment relating to participating in the PCEHR will be introduced from 1 May 2013 General practitioners can claim under the Medical Benefits Schedule when creating or changing a shared health summary, depending on the length of time it takes

should inform the development of Australia's PCEHR. However, there are marked differences between healthcare systems and the implementation of electronic records in other countries. For example, the Australian healthcare system has a mix of public and private health services, with consumers regularly moving between the different settings, and there is no requirement for consumers to register with one provider.

USA

Kaiser Permanente is a managed care organisation with nine million health plan members. It has developed the largest private shared electronic health record system in the world. The multibillion dollar information technology system connects 533 medical practices and 37 hospitals so that information can be shared between different sites and healthcare providers. The system includes bedside documentation for nursing staff, clinical decision support and bar codes for drug administration. It is used for each patient encounter by all health professionals in the organisation.

Consumers have complete or partial access to their records online or via their smartphones. They can securely email their doctor, book appointments online, refill prescriptions, access information about their condition and view most medical test results. Secure email messaging is an accepted part of healthcare provision and doctors and pharmacists see this as an efficient way of handling many routine issues.³ It has been associated with a decrease in office visits, an increase in measurable quality outcomes, and excellent patient satisfaction.^{4,5}

There is significant uptake of the system by consumers, with 63% of those eligible regularly accessing and using the system. Nine out of ten consumers with chronic conditions agreed the system enables them to more effectively manage their conditions.⁶ Consumers also report that the website helps them make informed decisions about their health and makes it more convenient for them to interact with their care teams.⁶

England

The Summary Care Record is an electronic patient record system in England that was developed as part of the National Health Service (NHS) National Programme for IT. In this system, patient information on drugs, allergies and adverse drug reactions is extracted from the general practitioner's computer and added to a centralised database, unless the consumer has 'opted out'.

Consumers can view the Summary Care Record online through a national portal (HealthSpace). They can also

amend elements of their personal medical information and add additional information.

An evaluation of the Summary Care Record showed that, when it was accessed, it seemed to support better quality care and increase clinician confidence in some encounters. However, there was no direct evidence of improved safety apart from some rare instances of averted medication errors.⁷ HealthSpace, the consumer component, was poorly taken up by consumers in England, most of whom perceived it as neither useful nor easy to use.⁸ They were disappointed with the amount and type of data available, the need to enter data themselves, and the limited options for sharing data with their clinician. Policy makers' hopes that HealthSpace would lead to personalised care, lower NHS costs, better data quality, improved health literacy and greater empowerment were not realised. HealthSpace will be closed in 2013.

Scotland

Scotland has implemented a simpler model for use only in after-hours and emergency situations. The Scottish Emergency Care Summary contains current drugs, allergies and adverse reactions. Data are automatically extracted twice daily from all Scottish general practices, which ensures the information is up to date. Patients can opt out of having their information uploaded and even when it is available, the information can only be accessed with the explicit consent of the patient for that episode of care. There is no consumer viewable component to the record at present.

Feedback from users is positive. Over 200 000 records are accessed every month and clinicians have found their decisions can be more timely, accurate, and patient centred.⁹

What can we learn from international experiences?

The purpose and long-term vision for the Australian PCEHR should be clearly communicated to facilitate acceptance by consumers and health professionals. Progress will depend on engaging consumers and clinicians. Providing value for consumers and health professionals is more likely to be achieved by undertaking ongoing evaluation which results in refinement and adaptation of the system according to their needs.

Data sharing

There is potential for the PCEHR to offer new ways for health professionals and consumers to share information effectively. Sharing and access to data could be particularly useful for those with chronic

conditions and with multiple healthcare providers or carers. This would also be useful in emergencies and when patients are moving between healthcare settings, especially as medication errors often occur in these situations.

Consent

The current opt-in consent model poses challenges for achieving a critical mass of users to make the system useful. An opt-out model for consumers would lead to more significant uptake, but this could only be achieved once trust in the system has been established.

Establishing trust in the security, accuracy and currency of the data in the system will be critical. Health professionals also have to opt in to the PCEHR. At present there is little perceived benefit in the PCEHR for a patient's usual clinicians who already communicate and share information.

Avoiding problems

Concerns have been raised about the potential for harms and unintended consequences associated with the introduction of the PCEHR and the need for preventive action to avoid these.¹⁰ An evaluation of the English Summary Care Record found instances of incomplete and inaccurate data, such as missing some drugs but including others that the patient was not actually taking.⁷ Clinician vigilance prevented harms from occurring in instances where there was incorrect or missing information. Accuracy and currency of data will be a particular challenge for the PCEHR when there are multiple sources of information. For example, medicines information may be contained in multiple documents (for example the shared health summary, specialists' letters and consumer-

entered notes). The challenge will be to synchronise this information to build a complete picture of the medicines that are being taken. An electronic system will not replace the need for the patient-clinician interaction to confirm the validity of the information contained in the PCEHR. In addition, as medical care involves more use of, and reliance upon, electronically recorded information, the same robust processes of clinical governance must apply to it as to all other products used in the healthcare sector.¹⁰ Safety governance for clinical information systems is long overdue.^{10,11}

Conclusion

Australia has taken the first steps towards a personal electronic health record. Some significant challenges have already been overcome, but there are more ahead. The key to success will be a common understanding of the purpose and potential of the new system – realistic expectations of what the system can achieve now and in future should be developed and communicated to both health professionals and consumers.

This is the start of an e-health evolution and progress will be incremental. It will be some time before benefits emerge. The PCEHR initiative will require long-term commitment and patience from consumers, clinicians and funders. ◀

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FURTHER READING

For more information on the PCEHR see www.ehealth.gov.au