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Author(s): Guy Donovan (of Holding Redlich)  
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## E-Health Records – where are we heading?

The issue of implementing a system for e-health records has again hit the headlines with the Australian Capital Territory Health Minister, Katy Gallagher, announcing a \$90.2 million investment in e-health. A central component of the health investment involves the development of a “Personal Electronic Health Records” (PEHR) system, with Ms Gallagher stating that “Personal Electronic Health Records will ensure that accurate and trusted personal health information is made available to the right person, at the right time to enable informed care and treatment decisions, which is better for patients and consumers, as well as health professionals and providers.”<sup>1</sup>

However, exactly what this means for health care consumers in the ACT and throughout Australia is not entirely clear at this point in time. Despite the many potential benefits in a PEHR system, it is largely still untested and many questions remain in relation to the implementation, benefits, cost and privacy aspects of e-health records.

### What is PEHR?

Essentially, PEHR is a person-controlled electronic health record that is shared with nominated health care providers.<sup>2</sup> It is currently not certain as to how a PEHR system in Australia will be implemented. However, in February 2008 the federal government established the National Health and Hospitals Reform Commission (NHHRC) to develop a long-term health reform plan for Australia, and a paper published by NHHRC in April 2009 provides some guidance as to the nature of a potential PEHR system.<sup>3</sup> The model proposed by NHHRC would see each consumer having a series of records linked by an individual identifier. The PEHR would be stored within distributed storage repositories, rather than a centralised database.

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<sup>1</sup> ACT Government media release, *\$90 million investment in an e-healthy future*, 5 May 2009

<sup>2</sup> National Health and Hospitals Reform Commission supplementary paper, *Person-controlled Electronic Health Records*, April 2009, p 11.

<sup>3</sup> Above note 2.

The system would allow the individual patient to contribute to their e-health records and permit sharing of the information with healthcare providers. In addition to the PEHR, the health service provider would maintain his or her own record of consultations with the healthcare consumer.<sup>4</sup>

### **Consumer benefits**

Regardless of the precise model that is implemented, the support from consumers for a new e-health record system has been widespread. It is believed that the current paper based health information systems are often disjointed and can lead to poor health outcomes. Accordingly, the development of a comprehensive e-health records system has the potential to assist in delivering better health care to consumers.<sup>5</sup>

A number of the key potential benefits of a PEHR system are worthy of note:

- Allowing consumers and health care providers to obtain easier access to health records;
- Improved safety through better access to more complete and accurate health information;
- Providing access to better co-ordinated and more timely health care, particularly for consumers in rural and remote areas;
- Enhancing the ability of consumers to actively participate in and manage their own health care;
- Reducing time spent searching or waiting for information from other providers relating to an individual's healthcare;
- Improving information sharing between health care providers to assist patient treatment;
- Reducing the reliance on the memory of individuals in relation to their own healthcare history;
- Reducing the need for duplication and repetition of histories and tests;
- Enabling greater use of clinical data for research purposes.

These potential benefits are clearly desirable in any health care system. However, the precise nature and implementation of the PEHR system will determine whether these benefits are readily available to consumers. It is within this context that many issues surrounding e-health record systems are currently being hotly debated.<sup>6</sup>

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<sup>4</sup> Office of the Privacy Commissioner, *Person-controlled Electronic Health Records – Supplementary Paper: Submission to the National Health and Hospitals Reform Commission*, May 2009, p 4.

<sup>5</sup> National Electronic Health Transition Authority, *Individual Electronic Health Record Consultation Report*, July 2008.

<sup>6</sup> The National Health and Hospitals Reform Commission has received over 600 submissions in relation to its report to be delivered to the federal Minister for Health, Nicola Roxon, in June 2009.

## Private or public infrastructure

Notably, the announcement of the ACT government's decision to deliver considerable funding to the development of a PEHR system has come just a short time before the NHHRC is due to release its final report and recommendations to the federal government. The NHHRC has already indicated its belief that the best means by which to implement an e-health records system is through commercial IT developers in an open competitive market.<sup>7</sup>

This approach appears to be favoured by the federal government, which until this point in time has been reluctant to allocate funds for a national e-health records infrastructure. Instead, the federal Health Department has indicated its intention to develop a legislative and regulatory framework allowing individuals to maintain their own electronic health records through commercial IT developers like Microsoft or Google.<sup>8</sup> This approach could have significant implications for the operation of PEHR.

It is arguable that consumers from rural and remote areas, the elderly and individuals with chronic illnesses could potentially derive the greatest benefit in their health care from an e-health records system. However, a lack of investment from the federal government may result in those groups missing out on the services provided in a user pays system.

Significantly, in July 2008 a report of the National E-Health Transition Authority Limited found that both clinicians and consumers strongly believe that it is the responsibility of the government to ensure that all Australians have access to an e-health records system.<sup>9</sup> In this context, the investment from the ACT government could be viewed as an enormous assistance to the development of an e-health records infrastructure. However, the federal government's lack of financial support for an e-health infrastructure leaves uncertainty surrounding the investment made by the ACT government. The hope for greater investment in an e-health records system from the federal government now seems to lie with the final report to be handed down by NHHRC later this year.

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<sup>7</sup> National Health and Hospitals Reform Commission supplementary paper, *Person-controlled Electronic Health Records*, April 2009, p 14, 17

<sup>8</sup> Dearne, Karen, *Budget 09: Patients sluggish with e-health bill?*, The Australian, 13 May 2009.

<sup>9</sup> National Electronic Health Transition Authority, *Individual Electronic Health Record Consultation Report*, July 2008, p 15

## **Technology**

An essential part of the implementation process of PEHR will be the technical issues involved in operating the system. The paper released by NHHRC in April 2009 stated that every Australian should be able to choose where and how their personal electronic health record will be stored, backed up and retrieved.<sup>10</sup>

To date, the public discussion in relation to e-health records has been largely at a high policy level with little debate surrounding specific technical issues. There appears to be many issues and potential problems that remain uncertain with the implementation of an e-health records infrastructure, including systems going off-line, backing up loss of data, difficulties in adding old records to the system, long term preservation and storage of records, hardware limitations and data corruption.

These are important technical issues that will need to be closely monitored. However, the relative silence in relation to these issues is of some concern given the indication from the federal government that any electronic health record system will be maintained through commercial IT developers. This may leave these technical issues, which have the potential to impact upon a consumer's health and privacy, largely outside the public eye.

## **Privacy concerns**

With the ease of flow of health information that is predicted with the PEHR system privacy concerns of individuals have taken great importance. It is essential that any electronic health records system ensure confidential, safe and ethical storing of information. In particular, privacy concerns have been raised for groups such as HIV or AIDs sufferers, individuals with mental health problems and women's groups.<sup>11</sup>

Interestingly, the proposed de-centralised PEHR system has been supported by the Office of the Privacy Commissioner and the Australian Privacy Foundation which submitted to the NHHRC that "a centralised database ... requires only a single point of failure to facilitate data breaches and the growing problem of identity fraud."<sup>12</sup> However, it could equally be suggested that the engagement of a number of commercial providers presents the potential for multiple privacy risks.

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<sup>10</sup> National Health and Hospitals Reform Commission supplementary paper, *Person-controlled Electronic Health Records*, April 2009, p 2

<sup>11</sup> Canberra Times, Electronic Records to Aid Health Treatment, 7 May 2009

<sup>12</sup> Australian Privacy Foundation, *Submission 37 to the National Health and Hospitals Reform Commission*, March 2009

This aside, one matter that has been widely agreed upon is the need for consumer control of e-health records to be underpinned by legislation. Currently, the *Privacy Act 1988* sets privacy standards for dealing with personal information and applies to the Commonwealth Government, the ACT Government and private sector organisations across Australia. However, if a national approach is to be implemented it is complicated by the range of laws applying to services throughout the states. In this context, the Office of the Privacy Commissioner has suggested a number of matters that should be included in a PEHR legislative framework:<sup>13</sup>

- Transparent and accountable governance mechanisms;
- Processes for consumer consent for access to records;
- Authorised and prohibited uses and disclosure of information collected;
- Arrangements for enforcing compliance with the standards that provide protection for privacy and security;
- Uniform complaint-handling mechanisms;
- Specific sanctions and remedies for privacy breaches.

It seems sensible that the privacy concerns surrounding an e-health records system be addressed by legislation. Further, there needs to be strong controls to regulate the collection and handling of health information not just for the protection of the consumer but also to assist in obtaining confidence in the service. This is particularly important in the context of a voluntary e-health records model as proposed by NHHRC. Ultimately, the system will require consumer support and if privacy concerns are not adequately addressed it is unlikely that it will obtain this support.

### **Consumer participation and control**

Whether any electronic records system should implement an “opt-in” or an “opt-out” model is a matter for further debate. The opt-out model is argued to ensure the maximum level of uptake and a reduction in costs and time burden associated with registration.<sup>14</sup>

However, with the protection of the individual consumer as a major concern the “opt-in” or voluntary system as proposed by NHHRC seems more appropriate. This model assists in allowing the decision to participate in the system to be free from coercion.

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<sup>13</sup> Office of the Privacy Commissioner, *Person-controlled Electronic Health Records – Supplementary Paper: Submission to the National Health and Hospitals Reform Commission*, May 2009, p 7.

<sup>14</sup> National Electronic Health Transition Authority, *Individual Electronic Health Record Consultation Report*, July 2008, p 14.

In addition to proposing a voluntary model, the NHHRC has also indicated that a person controlled electronic health record system will enable people to take a more active role in managing their health and making informed health care decisions.<sup>15</sup> Accordingly, any PEHR system that is implemented may encourage substantial consumer involvement in controlling access to their personal information and in making contributions to their records.

If the PEHR system is to provide the means for individuals to add information to their own records, clarity is needed as to how this aspect of the system will operate. It is very important the health providers have confidence in the e-health record system.<sup>16</sup> It must be clearly identified in the record as to who has provided the information recorded. Accordingly, a strong system of authentication and identification is necessary in the PEHR system.

### **Liability and medico-legal issues**

The precise nature of the control exercised by consumers over their medical records and the strength of identification and authentication systems also appears to be critically important in relation to liability for injury arising from medical treatment.

The interim report of the NHHRC noted that sub-optimal care can often be attributed to the fragmentation and failure to share information<sup>17</sup> and that 18 per cent of medical errors are a result of inadequate availability of patient information.<sup>18</sup> Accordingly, the implementation of an effective PEHR scheme has the potential to reduce these errors and there is no doubt that insurers will look at any PEHR system with great interest.

However, where questions can potentially arise as to the integrity of records, the source of information and the completeness of records it would be unwise for a health care provider to rely upon PEHR without checking the veracity and currency of the information with their patient.<sup>19</sup> Reliance upon PEHR without taking a client's history which results in sub-optimal treatment may leave the practitioner liable to civil claims for compensation.

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<sup>15</sup> National Health and Hospitals Reform Commission supplementary paper, *Person-controlled Electronic Health Records*, April 2009, p 1.

<sup>16</sup> Office of the Privacy Commissioner, *Person-controlled Electronic Health Records – Supplementary Paper: Submission to the National Health and Hospitals Reform Commission*, May 2009, p 7.

<sup>17</sup> National Health and Hospitals Reform Commission, *A Healthier Future for all Australians - Interim Report*, December 2008, p100

<sup>18</sup> Australian Institute of Health and Welfare, *Australia's Health*, 2002.

<sup>19</sup> National Health and Hospitals Reform Commission supplementary paper, *Person-controlled Electronic Health Records*, April 2009, p 13

Further, in personal injury claims for compensation the medical records of treating practitioners are important pieces of evidence. Accordingly, in a situation where a patient has “control” of his or her own health records issues of the integrity of records, the source of information and the completeness of records may again prove to be very important.

### **Conclusion**

The potential benefits of an effective and efficient PEHR system makes the announcement of the ACT government welcome news for consumers and health care providers. However, the question mark over the federal government’s commitment to funding e-health and the many, varied and complex issues involved in the implementation of a PEHR system means that Australia may yet be some way from seeing an effective and efficient system in place. The various issues such as consumer privacy and control should be debated vigorously to ensure that we ultimately receive an improved system for healthcare consumers.