

# Briefing Paper

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## HIV, Privacy and E-health

A policy briefing paper produced by the Australian Federation of AIDS Organisations

### OVERVIEW

A major component of Australia's e-health system will be the Personally Controlled Electronic Health Record (PCEHR), which along with the Individual Health Identifier – a unique 16 digit number all Australians have been allocated – is intended to provide the individual with their own health record which they are confident contains information that correctly corresponds to that individual. Consumers/Individuals will have the choice whether to opt-in to the system. According to the Minister for Health and Ageing, Nicola Roxon, people will have access to their e-health records from July 2012.<sup>1</sup>

The advent of a comprehensive e-health system promises great benefits for individuals and communities affected by HIV, given that people living with HIV (PLHIV) who have complex health conditions are frequent users of the health system, often managing a range of medical conditions. It is envisaged that health professionals in private practice, clinics and hospitals will be able to access information regarding past and present medical and psychiatric conditions - treatments, medications and care histories. Health professionals will be able to share information online rather than relying on referral letters.

Notwithstanding these benefits, the roll out of the e-health system raises significant potential issues for PLHIV, the most fundamental being privacy protections. In AFAO's submissions to the *Inquiry into the Adequacy of Protections for the Privacy of Australians Online* and on the exposure draft of the Healthcare Identifiers Bill 2010, we proposed that for people to choose to opt-in to the e-health system, it is essential that:

1. privacy protections exist, enabling users to select what information is linked to their e-health record, and who may have access to this information;
2. patients/consumers and health care providers trust the system functions; and
3. consent to opting in must be informed by an understanding of how the system works, the nature and extent of information that will be shared among health professionals, and the range of practitioners that may have access to the person's medical information.

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<sup>1</sup> Taylor, J. (2010, 8 July). Timetable confirms 2012 e-health date, ZDNet.com.au. Available at: <http://www.zdnet.com.au/timetable-confirms-2012-e-health-date-339304399.htm>

## E-HEALTH: perceived benefits and draw-backs

### Benefits

The primary benefit of the e-health system will be improved capacity for health care providers to share accurate information regarding a patient's:

- past and present medical and psychiatric conditions; and
- treatments, medications and care histories.

For people with cognitive conditions that affect memory and/or communication, it will be particularly useful to have an e-health record containing accurate medical information, including treatment histories and medications.

### Desire to protect privacy and create a user-friendly system

AFAO is aware that among our members and their constituents there are many who are enthusiastic about the benefits of e-health to ensure quality of care. However this enthusiasm can be tempered by concerns regarding privacy protections under the new e-health system, and about ease of use of the e-health system.

Some PLHIV are selective in disclosing health conditions and treatments to particular doctors and other health workers, to protect their privacy and avoid the stigmatisation that HIV can attract. For example, a person living with HIV may quite rationally be of the view that the fact they are HIV positive and being treated for depression, is none of their physiotherapist's business, nor the business of a doctor engaged by Centrelink to assess their work capacity. Similarly, an injecting drug user with hepatitis C may only wish to disclose their sero-status and/or drug use to particular health care providers.

The desire to conceal some personal information may stem from experiences of discrimination by health practitioners, such as GPs. According to the National LGBTI Health Alliance<sup>2</sup>, NSW research shows that GPs feel less comfortable dealing with gay & lesbian clients.<sup>3</sup> This discomfort can affect patients' experience of health care; HIV Futures studies conducted by the Australian Research Centre in Sex, Health and Society have consistently found that about a third of the PLHIV surveyed had experienced discrimination from health care services, and confidentiality of patient information has been among the most common problems reported.<sup>4</sup>

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<sup>2</sup> Khan, A., Plummer, D., Hussain, R. & Minichiello, V. (2008). Does physician bias effect the quality of care they deliver? Evidence in the care of sexually transmitted infections. *Sexually Transmitted Infections*, 84: 150-151, cited in National LGBTI Alliance (2010), Submission to Medicare Locals Consultation, p 5.

<sup>3</sup> For example, over two thirds of GPs were comfortable dealing with sexually transmitted infections among heterosexual and young patients, compared to less than half who were comfortable dealing with gay men and lesbians.

<sup>4</sup> Grierson, J., Thorpe, R., and Pitts, M. (2006). *HIV Futures 5: Life as we know it*, monograph series no. 60, The Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia, p. 68 <http://www.latrobe.edu.au/hiv-futures/HIV%20Futures%205%20Report.pdf>

It is essential to address these issues if PLHIV and affected communities are to have confidence in the e-health system, and enjoy its benefits.

## GOVERNMENT E-HEALTH AGENDA

The National Health and Hospitals Reform Commission (NHHRC) in its interim April 2009<sup>5</sup> report recommended the creation of ‘person-controlled [*sic*] electronic health records for every Australian’.

The Personally Controlled Electronic Health Record (PCEHR) is intended to provide<sup>6</sup>:

- summaries of patients’ health information - including medications, immunisations and medical test results;
- secure access for patients and health care providers to their e-health records via the internet, regardless of their physical location;
- rigorous governance and oversight to maintain privacy; and
- health care providers with the national standards, planning and core national infrastructure required to use the national e-health records system.

### **The Individual Health Identifier – the patient’s identifying number**

To facilitate the creation of the PCEHR the government introduced the Healthcare Identifiers Act 2010 (Cth), which commenced on 29 June 2010.<sup>7</sup> Under the legislation, all Australians have been allocated a unique 16 digit individual health identifier (IHI).

The health identifier is described as a basic building block of the e-health system, helping ‘to ensure individuals and providers can have confidence the right information is associated with the right individual at the point of care’.<sup>8</sup> According to the National E-Health Transition Authority (NEHTA), associated with an individual’s health identifier number will be a limited amount of identifying information such as, name, date of birth, and sex. In some circumstances, further data may be required (such as address, birth plurality and birth order, and aliases), to ensure unique assignment of the identifier number or to assist with the use of health identifiers.<sup>9</sup> It is intended that a person’s PCEHR will be accessed via individual healthcare identifiers to provide greater certainty that an individual’s information is being correctly attributed to their own electronic record, and to ensure

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<sup>5</sup> NHHRC media release. (2009, 30 April). *NHHRC Backs Person-controlled Electronic Health Records*. Available at: <http://www.health.gov.au/internet/nhhrc/publishing.nsf/Content/mediaRelease300409>

<sup>6</sup> Australian Government Department of Health and Ageing (2010, 11 May). *Personally Controlled Electronic Health Records for All Australians*. Available at: <http://www.health.gov.au/internet/budget/publishing.nsf/Content/budget2010-hmedia09.htm>

<sup>7</sup> Available at: <http://www.comlaw.gov.au/comlaw/Legislation/ActCompilation1.nsf/0/3F407B27709A1442CA257757008155A9?OpenDocument>

<sup>8</sup> Healthcare Identifiers Service – Frequently Asked Questions, Q 2. What does the Healthcare Identifiers Service mean for Australians? Available at:

<http://www.health.gov.au/internet/main/publishing.nsf/Content/pacd-ehealth-consultation-faqs>

<sup>9</sup> E-health, be at the centre of your healthcare, Health Identifiers, NEHTA, available at:

<http://www.ehealthinfo.gov.au/healthcare-identifiers/>

accurate communication of health information among health care providers.<sup>10</sup>

### **The Health Provider Identifier – the health care provider’s identifying number**

Under the new e-health program eligible health care providers and organisations will be assigned a Health Provider Identifier to support their unique identification. There will be two types of provider identifier: one type for individual health care professionals and other health personnel involved in patient care; and another for organisations such as hospitals or health clinics) where care is provided.<sup>11</sup>

Medicare Australia is the operator of the Health Identifier Service, and is responsible for implementing and maintaining the system, including the assignment of unique identifiers to health care providers and individuals.

### **What a Personally Controlled Electronic Health Record (PCEHR) will look like**

According to NEHTA<sup>12</sup>:

- the PCEHR is a secure, electronic record of an individual’s medical history, stored and shared in a network of connected systems;
- the PCEHR will bring together key health information from a number of different systems and present it in a single view;
- information in a PCEHR will be able to be accessed by the individual and their authorised health care providers. With this information available, health care providers will be able to make decisions about the individual’s health and treatment. Over time the individual will be able to contribute to their own information and add to the recorded information stored in their PCEHR<sup>13</sup>;
- the PCEHR will not hold all the information held in the individual’s health care professional’s records but will complement those records by highlighting key information. (It is not clear who would decide what the key information is that would be part of the PCEHR. It is essential for this to be clarified so that all users of the system understand how it operates); and
- in the future, as the PCEHR becomes more widely available, individuals will be able to access their own health information from anywhere in Australia.

The government has announced that by July 2012 PCEHRs will be available to individuals who would like a PCEHR. The government has foreshadowed consultations in the beginning of 2011 to explore details of how PCEHR will evolve. Three lead implementation sites have been created in the Brisbane, Melbourne and Hunter regions. It is envisaged that implementation sites will be made up of health sector organisations partnering to establish a community of interest focused on implementing PCEHR components that support sharing or aggregation of electronic health

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<sup>10</sup> Healthcare Identifiers Service, Medicare Australia, at: <http://www.medicareaustralia.gov.au/public/health-identifier/files/healthcare-identifiers-brochure.pdf>

<sup>11</sup> E-health, be at the centre of your healthcare, FAQs, NEHTA. at: <http://www.ehealthinfo.gov.au/faqs/>

<sup>12</sup> What is a PCEHR?, NEHTA, at: <http://www.nehta.gov.au/ehealth-implementation/what-is-a-pcher>

<sup>13</sup> How individuals will contribute information has not yet been made clear, see Guy Donovan, E-Health Records – where are we heading?, *Australian Health Law Bulletin* 2009, p. 6. Available at: <http://www.holdingredlich.com.au/assets/docs/e-health-records-where-are-we-heading.pdf>

information at a geographic or sector functional level, such as health record repositories, discharge summary capabilities or medications management capabilities.<sup>14</sup> It is essential that these lead implementation sites test model scenarios of how the e-health system will play out of individuals with complex health needs and/or conditions that attract stigma, such as people living with HIV and affected communities.

### **Central database versus distributed repository**

An electronic health system is sometimes associated with the idea of holding all an individual's health records in a single database. A serious cause of concern for some privacy advocates is that if a security breach of a central database of this type occurred, through hacking for example, the hacker would potentially have access to all of the individual's health information. It is also argued that the richer the information stored in any one place, the greater the incentive to hack that information - sometimes referred to as the 'honey-pot' effect.

It seems that the model envisaged under the government's e-health initiative is a distributed repository rather than a central database. According to Health Minister Roxon, the PCEHR would not involve the creation of 'massive data repository'. Instead, the system would link data held in a GP's systems, at the pharmacy and within hospitals.<sup>15</sup>

## **PRIVACY, HIV AND E-HEALTH**

According to NEHTA, privacy 'is one of the key priorities leading up to the widespread adoption of e-health in Australia'<sup>16</sup>. NEHTA has developed six privacy standards to guide the development of e-health. One standard, entitled 'Individual participation', advises that individuals:

.... will have greater control over the way health information is collected and accessed. No unauthorised person will be able to access your own details enabling you to have greater confidence in how health data can be used and exchanged seamlessly for the right purpose.

Such assurances regarding individual access and control lead to further questions - about how individuals will be able to control the linkage of data accessible via their identifier, namely:

- who decides what information is linked?
- who can access that information?
- how is that information accessed?

It is also not clear how individuals will exercise any control, and what mechanisms will allow them to do so.

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<sup>14</sup> NEHTA Home - eHealth Implementation - PCEHR Lead Sites. Available at: <http://www.nehta.gov.au/ehealth-implementation/pcehr-lead-sites>

<sup>15</sup> Dearne, K. (2010, December 7) Leak of draft e-health document raises privacy concerns, *The Australian*. Available at: <http://www.theaustralian.com.au/australian-it/leak-of-draft-e-health-document-raises-privacy-concerns/story-e6frgakx-1225966635891>

<sup>16</sup> NEHTA Home - Connecting Australia – Privacy. Available at: <http://www.nehta.gov.au/connecting-australia/privacy>

## **Need for modelling**

AFAO believes that detailed modelling is required to test the efficacy of proposed privacy protections for people with particular privacy issues, such as a people living with HIV. The modelling should include scenarios to show how e-health system policies and practices will ensure compliance with Commonwealth and state/territory privacy legislation, as well as privacy legislation specifically dealing with HIV. As acknowledged in the government's response to the Australian Law Reform Commission's Recommendations, this interplay is complex.

The HIV surveillance system is a case in point. Without modelling, it is difficult to envisage how the e-health system will operate along-side (or together with) HIV surveillance and the task of explaining e-health *and* surveillance system privacy protections to people with HIV will be difficult. The following hypothetical scenarios illustrate the complex circumstances and important privacy issues that need to be addressed in order to ensure that privacy and security concerns of people living with and at risk-of HIV are addressed in the e-health system, including under the proposed PCEHR.

### **HYPOTHETICAL SCENARIOS:**

#### **1. Juan**

Juan is 57 and has been living with HIV since 1990. He also has mild cognitive impairment which has been diagnosed as HIV related. Under the care of a specialist medical practitioner, Juan's health is well-managed and Juan generally enjoys a good quality of life. He and his partner live in Sydney but plan to spend time in Tasmania to be near his partner's ageing mother. Juan will continue to be cared for by his health care professionals in Sydney but wants to have access to his medical record in case there is any problem while in Tasmania. While he does not mind showing a new health care professional his e-health information about his cognitive impairment, he does not want any HIV-related information to be immediately accessible/visible. This is because of a previous negative experience in which a health-care worker he didn't know very well disclosed Juan's HIV status to a member of his family. He would only like to disclose his HIV-related information once he feels he can trust the particular health-care worker. His specialist medical practitioner also suggests to Juan that he updates his health record with relevant health information. Key issues in relation to Juan's privacy and his e-health record that arise include:

- Will Juan be able to decide what information is linked? Will he be able to edit this information at any time? If so, how?
- Will Juan be able to restrict who can view his HIV-related health information? If so, how?
- Will Juan, at a later time, be able to authorise a new health care worker to view his HIV-related health information? If so how?
- What type of information will he be capable of updating himself, as suggested by his specialist medical practitioner?
- Will Juan be capable of updating his own health record, in terms of computer literacy, and general accessibility? If so, how?

## 2. Ruth

Ruth is a 30 year old Aboriginal woman, with 2 daughters. She has previously injected drugs and recently found out that a friend with whom she had shared syringes has HIV. She does not wish to go the local Aboriginal Medical Service where she usually has her health check-ups and consultations as her sister-in-law works there. Ruth doesn't want her sister to see her medical record containing information about her drug use and HIV test. She therefore chooses to go to the nearest sexual health clinic for an HIV test and she receives a positive diagnosis. Aside from the pressing HIV treatment and support related matters, key issues that arise in relation to Ruth's privacy include:

- Will the sexual health worker be able to explain how Ruth's health-related HIV information will be used for both the mandatory surveillance system and the voluntary e-health system?
- Will the sexual health worker be able to explain how the clinic's health record, the e-health system, and the PCEHR specifically, work and inter-relate?
- Will the sexual health worker ask Ruth whether she wishes to have the clinic's health record linked to her PCEHR?
- If the sexual health worker agrees not to record Ruth's HIV status on her PCEHR at her request, will the sexual-health worker discuss with Ruth whether a record of her HIV-related medications will be linked to her e-health record, explaining the inferences that may be drawn from medication information alone?

As discussed in AFAO's submission on the *Adequacy of Protections for the Privacy of Australians Online*, in establishing the new e-health system two key aspects must be addressed to ensure that individual/consumers who wish to use the system can do so safely and confidently. They are:

- Functionality ensuring privacy
- Usability for individuals/consumers

### **Functionality ensuring privacy**

It is essential that the design of the e-health system reflects the needs and desires of individuals/consumers. Important questions to consider include:

- What information would individuals/consumers like to have included?
- What information should be able to be hidden?
- Is it desirable that with every interface with the PCEHR system, individuals/consumers select each piece of information they want visible?
- How will the integrity of the current anonymous HIV surveillance system be maintained (and explained to people – especially to people from at-risk communities)?

### **Usability for individuals/consumers**

To engage individuals/consumers, the PCEHR - and the e-health system more broadly - must be user-friendly. If people who would potentially greatly benefit from the system are to opt-in to the system, they must trust the system, and they therefore must understand it. The roll-out of the e-health

system, including the PCEHR, should thus address the following issues:

**1) Supporting health care providers to explain the e-health system**

It is reasonable to assume that health care providers will be expected to try to persuade their patients to opt-in to the new e-health system. As part of this, they will need to address any privacy concerns regarding the e-health system, including explaining the role of the PCEHR. Health care providers will have a particular responsibility to explain the initiative very carefully to patients who are shocked by a diagnosis, people who are mentally ill, people with dementia, and people with an acquired brain injury or any condition affecting cognition or intellectual capacity, in order to obtain informed consent to opt in to the system.

The health care provider must have time and resources to assist in explaining e-health in clear language; doing so will pose challenges in a hurried health-care context where, for example, a GP may be giving an HIV diagnosis, advising of treatment options and support services and explaining HIV surveillance privacy protections.

**2) E-health guidance and tools for individuals/consumers and health care workers**

As part of the roll-out of the e-health system, relevant government bodies must provide educational materials that clearly and precisely explain the workings of the e-health system. A variety of media should be considered, including brochures, short video explanations, an enquiry phone-line and public outreach through community meetings and discussions. It is crucial to create targeted materials and tools for individuals/consumers with low general and electronic-literacy, cognition, low-income and those from culturally and linguistically diverse backgrounds.

**3) Community organisations educating their own communities**

To best explain to individuals/consumers this significant change to the healthcare system, consideration should be given to resourcing community organisations/service providers to educate and engage their own communities. AFAO member organisations are strategically placed to undertake such education about the new e-health system and may be able to address any community concerns about e-health, including privacy and government control of their personal information.

**Further information on e-health:**

Consumer Health Forum: [www.chf.org.au](http://www.chf.org.au) or on 02 6273 5444

National E-health Transition Authority: [www.nehta.gov.au](http://www.nehta.gov.au) or on (02) 8298 2600

Department of Health and Ageing: [www.doha.gov.au](http://www.doha.gov.au) or on 1800 020 103