

PositiveLifeNSW

the voice of people with HIV since 1988

Draft Concept of Operations: Relating to the introduction of the personally controlled electronic health record (PCEHR) system

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About Positive Life NSW

Positive Life NSW is a community-based non-government organisation that has represented the interests of people with HIV in NSW since 1988. Positive Life NSW provides advocacy and representation to government and non-government agencies on HIV-related issues. It also provides HIV prevention, education and support programs that focus on improving the health and wellbeing of people with HIV in NSW. Positive Life NSW works to eliminate the prejudice, isolation and discrimination experienced by people with and affected by HIV in NSW.

People with HIV in NSW

The total number of people diagnosed with HIV in Australia was estimated to be 20,956 in 2010. By 2020, the total number of people living with HIV in Australia is predicted to be 28,422. This does not account for the 10-20% of HIV infections that are thought to be undiagnosed¹. NSW is the state with the highest number of people living with HIV, with 9,924 people in 2010, estimated to increase to 11,721 by 2020².

Benefits and drawbacks of the PCEHR

The introduction of a personally-controlled electronic health record system offers considerable benefits for individuals and communities living with HIV. People with HIV manage a range of complex health conditions and are frequent users of health services. The PCEHR has the potential to improve the fragmentation and duplication of health information and provide individuals with greater access to and control over their health information and management. The PCEHR also

¹ Wilson D. Mapping HIV outcomes: geographical and clinical forecasts of numbers of people living with HIV in Australia. National centre in HIV Epidemiology and Clinical Research, National Association of People Living with HIV/AIDS, 2010, p 5

² Ibid, p5

has the potential to improve continuity of care, improve diagnostic and treatment capabilities and improve care coordination for individuals with chronic and complex conditions. By allowing them and their health care providers to make better-informed decisions about their care and service coordination, better health outcomes will be achieved for individuals and populations.

Positive Life NSW is aware that while some people with HIV will be enthusiastic about the PCEHR and embrace the system's benefits, there will be others who have concerns about privacy. Many people with HIV are selective about disclosing their HIV and other health conditions (and treatments) to doctors and allied health workers. These decisions are rationally made to avoid the stigmatisation that HIV can sometimes attract. The wish to conceal elements of personal health information can emanate from previous experiences of discrimination by health care providers. Research conducted by the Australian Research Centre in Sex, Health and Society has consistently found that about one quarter of the survey respondents had experienced less favourable treatment at a medical service as a result of having HIV. Ten percent of these respondents had experienced discrimination in the last two years³. These percentages have remained virtually unchanged over a 10-year period.

To this end, Positive Life NSW supports individuals exercising greater personal control over their health information by having the options to:

- Decide whether or not to have an active PCEHR
- Be able to access information in their PCEHR
- Set controls around health provider access
- Authorise others to access their PCEHR
- View an activity history of their PCEHR
- Make enquiries and complaints in relation to the management of personal information in the PCEHR and the PCEHR system in general
- Decide to opt out of the PCEHR.

Deciding whether or not to have a PCEHR

Notwithstanding the benefits outlined above, the introduction and effective use of the PCEHR system raises significant issues for individuals and communities affected by HIV.

For some people with HIV, the decision to either opt in or opt out of the PCEHR will be a complex and difficult one. Consent to opting in to a PCEHR must be informed by an understanding of how the system works, the nature and extent of the information that will be shared amongst health professionals and the range of practitioners that might have access to the person's medical information. For

³ Greirson J, Thorpe R, Mitts, M. (2006). HIV Futures 6: Making positive lives count, Monograph Series Number 74. The Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia, p 58

individuals with HIV who have sensitivities around privacy and confidentiality, providing informed consent will be crucial. For people who have mental health conditions, drug and alcohol issues or a range of cognitive impairments, the issue of obtaining informed consent becomes more challenging and will need to be carefully considered.

Health care provider access controls

Providing options for consumers to set controls around healthcare provider access is commendable. However, it should be noted that significant numbers of people with HIV will be selective about disclosing their health conditions and treatments to different sections of the health workforce. They will want to make an informed consent and exercise all their options about which healthcare providers have access to different clinical repositories of information. People with HIV may have sensitivities about specific aspects of health information contained in Shared Health Summaries. They may also wish to limit access to Event Summaries, Specialist Letters, Pathology Result Reports and Prescribing and Dispensing information by some healthcare providers.

Although the PCEHR system proposes to treat all clinical documents as potentially sensitive health information and provide the individual with a number of options around how each document should be handled, the onus is on the individual to inform the healthcare provider that they do or do not want a clinical document loaded onto their PCEHR. In this environment, it will be essential to provide adequate education and training to potential PCEHR users to effectively manage:

- The 'Include' and 'Exclude' list of healthcare organisations
- Who will be their nominated provider and what information will be viewable in the "consolidated view" and the "shared health summary"
- Options around controlling access for:
 - General access to clinical documents
 - Limited access
 - No access
- Opting out of the PCEHR
- Making a complaint.

In the case of options around control access settings for clinical documents, use of the system's options will require knowledge and careful consideration in terms of balancing privacy concerns against unintended clinical consequences resulting from "limited access" or "no access" control settings.

Clinicians should be supported by their desktop systems to allow them (with consent of the patient) to change the access level at the time the document is created. This would mean that individual clinicians such as intravenous drug clinicians or sexual health clinicians could default their documents to "Limited Access" or "No Access" if that was the decision of the patient. This option is especially important for large multidisciplinary practices (medical centres) and

hospitals and would cut down on the need for re-classification of documents that a consumer would need to make post-consultation for privacy reasons. For example, this option would support consumers who want their HIV consultation classified as "limited Access" or "no Access", but have their fracture clinic or wound care or Emergency Department presentation "General Access".

When granting access to a Nominated Representative, consumers should have the option to limit access to information. Nominated Representatives should not have the ability to change access settings, as this is giving them the ability to override consent that only the consumer has the right to make or to withdraw.

In the case of Advance Care Directives, we suggest that the system supports the ability to record not only the location and custodian of the Advanced Care Directive, but the broad nature of the directive, the creation date of the record and a confirmation date.

Privacy and security

Successful delivery and uptake of the PCEHR by people with HIV will be dependent upon the development of trust and confidence in the system. Individuals will require an understanding of and familiarity with the system if they are to exercise control over their health information. This will limit inappropriate access to sensitive information. A thorough understanding by consumers of the functional operations and potential control settings of the PCEHR system will be vital to ensure that trust and confidence in the system is fostered.

Education, informed consent and uptake of the PCEHR

To engage individual consumers, the PCEHR must be user-friendly. People must trust and understand the system and its functionality. The roll-out of the PCEHR will therefore need to address the following issues:

- It is reasonable to assume that health care providers will try and persuade their patients to opt in to the new PCEHR. They will therefore need to address any privacy concerns regarding the PCEHR, including explaining the role of the PCEHR, who can have access to health information and what controls the individual has to limit access to sensitive information. They will also need to explain that an opt-out option is available. Health care providers will have a particular responsibility to explain carefully to patients who have mental health conditions, intellectual or learning disabilities and cognitive impairments in order to obtain informed consent to either opt in or opt out of the PCEHR system.
- As part of the PCEHR roll-out, relevant government agencies must provide educational materials that clearly and precisely explain the working of the PCEHR system. This will be particularly important for individuals who decide to register for a PCEHR online. A variety of educational media should be considered, including brochures, short video

explanations and outreach through community meetings, discussion and print media. It will be crucial to create targeted educational materials for individuals with low literacy, cognition impairment and for those from culturally and linguistically diverse backgrounds.

- Community organisations are strategically placed to undertake education initiatives and overcome community concerns about the PCEHR, security and control over their personal health information.

Use of the PCEHR for research

Positive Life NSW is aware that the PCEHR will contain potentially rich sources of clinical and health-related data. It is reasonable to assume that there will be discussions about the use of this data for research purposes. Research would only be acceptable if all data was de-identified and subject to appropriate national oversight by the NHMRC Ethics Committee. Informed consumer consent will be required from individuals registering for the PCEHR at the inception of the system if research is to be conducted by either government or other agencies. Access to PCEHR data for research should be subject to a separate informed consent process.

Governance

Positive Life NSW notes that:

The PCEHR system's governance arrangements, regulatory framework, including complaints management and sanctions are being developed by government and will be informed by the Concept of Operations consultation process and will be the subject of a later consultation process.

There is currently no mention in the *Draft Concept of Operations* regarding penalties for inappropriate access or security negligence on the part of either Providers or Service Operators. Positive Life believes that there must be real penalties for breaches of privacy and security by providers and service operators.

It will be essential that individuals are able to lodge complaints about suspicious or unauthorised access of their PCEHR if confidence in the system is to be generated and maintained. A single nationwide complaints and investigation body is the preferred option.

Positive Life NSW will be interested to provide further comment when the PCEHR system's governance arrangements, regulatory framework, including complaints management and sanctions, have been developed.

Conclusion

Positive Life NSW would like to thank the Department of Health and Ageing and the National E-Health Transition Authority for the opportunity to comment on the *Draft Concept of Operations for the PCEHR System*.

Positive Life NSW agrees that the PCEHR system offers a number of potential benefits for individuals and communities living with HIV who manage a range of complex health conditions and are reliant on health services. Informed consent will be crucial to decisions by consumers about whether to opt in and register for a PCEHR or not. In the case of people with HIV, these decisions will be difficult. Many have experienced stigma and discrimination and have concerns about privacy. Additionally, the PCEHR system is complex. If consumers are to have confidence in the PCEHR, decisions to opt in and utilise the previously stated benefits will require a thorough understanding of the system drivers and particularly the use of access control settings. For people with mental health conditions, learning and intellectual deficits or cognitive impairments, providing informed consent and using the PCEHR will be a challenge. Providing adequate education for consumers and support for clinicians to discuss with patients the pros and cons of the PCEHR will be important factors in building confidence and uptake of the system.

Recommendations:

- 1) That healthcare providers are resourced and supported to engage consumers in a process of informed consent, including:
 - the role of the PCEHR
 - the opt in/opt out options
 - who can have access to health information and under what circumstances
 - privacy and sensitive health information
 - the use of access controls by consumers and the control of sensitive information.
- 2) That clinicians be supported by their desktop systems to allow them (after discussion and with consent of the patient) to change the access level of clinical documents (for inclusion in the PCEHR) at the time that the document is created.
- 3) That relevant government agencies provide a range of educational materials across a wide range of media to clearly and precisely explain the PCEHR system and assist informed consent by consumers.
- 4) That community organisations are resourced to engage and educate their communities about the PCEHR.

- 5) That research using PCEHR data is subject to appropriate national oversight by the NHMRC Ethics Committee and agreed to by consumers during registration.

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Yours sincerely
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