

3 August 2011

Submissions in response to the Legislative Issues Paper relating to the PCEHR

These submissions are made jointly by Positive Life NSW, the representative community organisation for people with HIV in NSW, Hepatitis NSW and the HIV/AIDS Legal Centre (HALC), a specialist Community Legal Centre. Information about Positive Life NSW, Hepatitis NSW and HALC is found in attachments A, B and C.

Approach

While it is recognised that the PCEHR bears considerable potential benefits for people with complex health issues, including people with HIV (see attachment D), its uptake will rely on those target populations having confidence in effective protections being built into the PCEHR system in relation to privacy.

Privacy and confidentiality between a patient and a clinician is paramount to fostering a relationship of clinical trust and candour. Specific care has been directed to engendering 'safety' in the confidentiality of the information given within the context of the clinical relationship. In the context of HIV, the relationship between patient and healthcare provider becomes of particular significance. The quality of this relationship is fundamental to the healthcare of the individual and to public health. To enable frank disclosure between patient and clinician, confidentiality in relation to HIV testing, diagnosis and treatment is protected by special provision (section 17) of the Public Health Act (1991) NSWⁱ and making an unauthorised disclosure is a criminal offence.

The rationale for the emphasis on privacy and confidentiality relates to the highly stigmatised nature of HIV and to the vulnerability and social exclusion of the populations that are most at risk and affected (homosexual men, intravenous drug users etc.) There are intersections between these factors and the target groups (e.g. those with chronic illness) that have been identified for the PCEHR.

Although the relationship between confidentiality, privacy and the clinical relationship is a subtle one, it is recognised as a powerful driver of HIV testing and treatment uptake, which in turn relies on full and frank disclosure of behaviour to medical practitioners.

This submission

This submission will focus on:

Privacy
Security
Remedies
Penalties

Privacy – use and disclosure of information**Proposal 34****Q 24, Q26**

The benefit of the PCEHR, in centralising medical records is also a potential issue for privacy. The PCEHR focuses and amplifies access to a person's medical records through a single and convenient interface.

Subpoena of medical records

The potential of subpoena of medical records is a real and significant consideration for some vulnerable populations when dealing with medical practitioners. This is particularly so for people with HIV, hepatitis B and C, other sexually transmitted infections and mental health conditions. One does not have to travel far back in time to recall when homosexuality was illegal. Medical records would be relevant to medical investigation and could be subject to subpoena and criminal investigation. Transgender, intravenous drug-using, gay/MSM, HIV positive and sex worker patients are populations whose activities might attract (historically or into the future) criminal investigation that is reliant upon medical records for substantiation. If the purpose of the PCEHR is to enhance patient care and not amplify patient vulnerability, the system should be immune from direct or secondary access via subpoena. This means that print records taken from the PCEHR or information derived from material sourced from the PCEHR would be inadmissible.

Similar protections are provided by the Commonwealth for epidemiological studies under the Epidemiological Studies (Confidentiality) Act 1981.

We would extend this protection still further and provide in the legislation that at no time may the PCEHR be accessed or used for the purpose of investigation of criminal offences or conduct. The PCEHR should not enhance the vulnerability of highest needs populations. The PCEHR should be immune from subpoena in all jurisdictions and facilitate better healthcare.

Mechanisms and triggers already exist for health care providers who come to know of serious criminality potentially putting others at risk to initiate processes to address such behaviours. In extreme cases, breach of confidentiality is ethically and legally required. Those mechanisms are part of an enabling environment which allows people to engage frankly with their clinician with the assurance of confidentiality. Within the context of

HIV, policies for management of people who place others at risk apply and are effective nationally. Availability of the PCEHR as a catch all source of evidence to found criminal prosecutions potentially undermines the effective basis and workings of those public health policies. This situation was recently seen, as we understand it, in one jurisdiction where police subpoenaed files from an HIV service organisation and then followed up with prosecutions on matters which had previously been effectively dealt with and contained under the State Public Health provisions.

It will remain the case that health records may be subpoenaed directly from healthcare providers where criminality is alleged. Allowing the PCEHR to be subpoenaed amplifies the availability of this process for 'fishing expeditions', at the same time increasing the vulnerability of 'at risk' patients and undermining confidence in the 'safety' of the clinical relationship.

It goes without saying that any data used for other than primary healthcare purposes should be protected. Only de-identified data extracted from the PCEHR should be allowed for research or other purposes.

Access by principles

Personal control – Proposal 25

The current proposal for personal control of the PCEHR allows for a range of access control settings that support individuals exercising greater control over their health information (including opt-in and opt-out and setting controls for health provider access). The PCEHR system is inherently complex. In the context of guardedness and poor consumer health literacy in relation to medical records in general, we believe that many people from vulnerable population groups (including people with mental health conditions) will fail to proactively control their PCEHR access control settings and effectively disengage after registration. To address this situation, we would support a periodic renewal process where consumers are prompted to restore and reactivate their PCEHR. Such a system would ensure that individual control truly resides with the patient. Reengagement would engender a process of informed and active consent to the system by patients and does not rely on apathy or lack of knowledge for 'participation' by consumers.

Additionally, renewal would provide an opportunity for medical attendants to discuss the benefits or otherwise of participation in the system with patients and to identify areas of medical information that are considered sensitive by patients and not to be uploaded to the PCEHR. Adequate additional resourcing of healthcare providers via a new Medicare item to facilitate PCEHR discussions is warranted in our opinion.

Access by others

Proposals 3-5 indicate how authorised representatives may be permitted to access the PCEHR. There remains an issue for many of our constituency of maintaining their privacy after death.

Proposal 24 deals with the retention of the records after the last action.

Due to the stigmatised nature of HIV and HCV, many of our constituents choose not to disclose their status even to their close family and friends. There is often a desire for such privacy to subsist after death. Sometimes circumstances necessitate post-mortem disclosure of health status to family and close others. Oftentimes though, people will manage their affairs as to prevent disclosure to close family and friends even after death.

We would like to see the ability of a participant to have their PCEHR removed after death. This would not affect the retention requirement relating to records held by healthcare providers; however it would provide a level of subsisting privacy making it easier for a person to prevent unwanted disclosure of their status to close family, their executor or administrator of their estate.

Healthcare provider organisations Security - Q 15

The **Proposals 9-11** provide some detail in relation to the conditions which will apply to healthcare provider organisations. Security around an individual's PCEHR and access by other individuals within a healthcare provider organisation, such as contracted service providers and administrative staff, is less clear however. In the case of large multi-disciplinary centres (medical centres and hospitals) individuals may grant access to a specific healthcare provider (specialist) but not want their medical records viewed by other staff in the healthcare provider organisation. It is not clear how much information a patient viewed activity history will include. The activity history should allow the patient to review their PCEHR access history (by whom, when, and why it has occurred). This should include the name of the healthcare provider organisation, the name and role (e.g. doctor, nurse, administrator, etc.) of the officer accessing the record and a descriptive of the reason/context for accessing the record. An 'individual within a healthcare provider' organisation's 'legitimate need to access the PCEHR system' should be amenable to a description, other than by a drop down menu of reasons. This audit trail should allow for tracing the actual documents or parts of the record accessed.

Privacy - coverage and Remedies Q22

The current Commonwealth Privacy Act does not provide the necessary level of protection for personal information uploaded to the PCEHR. Under current Commonwealth Privacy legislation (as we understand it) there is no review right or right to a hearing before a court or tribunal on the substance of the complaint where the Privacy Commissioner has dismissed the complaint.

This complaint process is a *cul de sac* for complainants and there is no right to a 'hearing' under the processes of the Privacy Act. The system is not transparent, is overly complicated for complainants and unsatisfactory in delivering remedies for people whose privacy has been breached (usually by organisations). The NSW State Privacy Act and Health Records Personal Information Privacy Act are similarly flawed. Other states' privacy provisions may be better, although this is doubtful.

Fortunately for our constituents (people with HIV and hepatitis C), their privacy complaints may be recast as an anti-discrimination complaint. That jurisdiction, both federally and in NSW, provides a much better system of remedy for a privacy breach.

Not all participants in the PCEHR will have alternative remedies available. This system deserves a real, effective and accessible remedy for breach of privacy. The current Commonwealth Privacy Act does not provide adequate protections or remedies.

Adequate provision for remedy for breach of privacy would include the right to a hearing and review before a tribunal or court in a 'no-cost', low legal technicality context.

Notwithstanding the foregoing, we support the draw-in provisions in **Proposals 31 and Proposal 32** in so far as they bring operators within jurisdiction of federal remedies such as they are.

Offences and Penalties – Proposal 36

In creating a system with protections it is important to allow for effective penalties. Penalties should be able to be directed jointly and severally to individuals and organisations without restrictive technicality.

Provision should be made for recalcitrant or repeat offenders to be removed from the system and for patients with some interaction with that healthcare provider organisation, or individual healthcare providers, to be advised of the removal and the (generalised) reasons for the removal.

We believe that it is entirely appropriate to impose a penalty on an individual who requests a record from the PCEHR system when not entitled to do so. The penalty should be severe enough to act as public deterrent to inappropriate access and use of information contained in an individual's PCEHR.

Proposal 38

Q 31 and 32

There should be an obligation of confidentiality over the information a system operator holds, obtains, transfers or uses via the PCEHR. This entrenches the value and function of the authority/consent provided by a patient to allow and limit the disclosure of information. Such a provision may act as a catch all where the access to, and use of the

information by, a system operator using the PCEHR may not clearly fall under protections in other state or federal privacy or information protective instruments.

Specific points of contention in disputes over breaches of information protective legislation may be *inter alia* over the concepts of whether the use of information is for a primary and secondary purpose; whether and to whom there is provision of a service; and whether information may be considered unsolicited information. Having no express duty of confidentiality placed upon the system operator is likely to allow gaps in the privacy protection provisions, reducing their effectiveness.

Protections currently in place usually relate to control and use of information where a direct relationship exists between the patient (giver) and medical provider (recipient) and a shared or understood purpose for the information transfer. Once the PCEHR becomes the conduit for the information, that direct relationship is not present and the legal relationships will change and the protections may be ineffective upon system operators.

We support that there be a clear indication of the duty of confidentiality existing, and clear provisions indicating breaches and remedies. We are concerned that reliance on generality of existing privacy legislation to cover issues arising under this novel instrument (the PCEHR) may be inadequate protection.

Conclusion

Positive Life NSW and the HIV/AIDS Legal Centre (HALC) would like to thank the Department of Health and Ageing for the opportunity to comment on the *Personally Controlled Electronic Health Record System: Legislation Issues Paper*.

Further information

If you require further information in relation to this submission, please contact either Lance Feeney at Positive Life NSW on (02) 9361 6011 or email lancef@positivelife.org.au, or Brady at HALC on (02) 9206 2060, or email brady@halc.org.au

Recommendations:

- Serious consideration should be given to making the PCEHR immune from subpoena in all jurisdictions.
- Use of the PCEHR for criminal investigation should be forbidden.
- We support a periodic renewal process whereby consumers are prompted to restore and reactivate their PCEHR. We suggest a periodic renewal of one to

two years, the period increasing over time, as confidence in the PCEHR and use of the control settings increases.

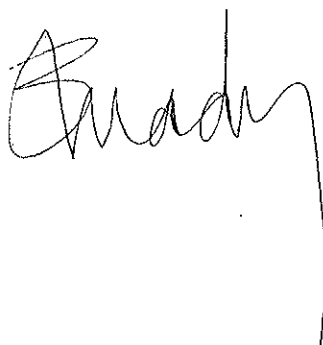
- The activity history should allow consumers to review their PCEHR access history (by whom, when and why it has occurred). This should include the name of the healthcare provider organisation, the name and role of the officer accessing the record and a descriptive of the reason/context for accessing the record.
- Adequate provision for remedy of a breach of privacy should include the right to a hearing and review before a tribunal or court in a 'no-cost', low legal technicality context.
- Offences and penalties under the PCEHR should be adequate to ensure compliance with privacy expectations of the community standards. Provisions should be made flexible and practical so as to adequately address breaches. Provision should be made for exclusion of repeat/recalcitrant offenders, and for informing patients possibly affected by the perpetrator of systemic or a serious information confidentiality or security breach.
- The PCEHR should have its own confidentiality requirement for use at all levels of operation. Confidentiality under the PCEHR should not hinge on other or existing systems where their adequate extension to issues of use/misuse of information under the PCEHR may not be assured.

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Attachment A

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 on-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.

Attachment B

Hepatitis NSW (formerly the Hepatitis Council of NSW) are the peak community-based hepatitis organisation in New South Wales. Hepatitis NSW take a partnership approach with people primarily affected by hepatitis C and those working with it.

Attachment C

The HIV/AIDS Legal Centre Inc NSW (HALC) was started in 1992 as a specialist Legal Centre to respond to HIV related legal matters, issues and policy. HALC has expanded its operations to include Hepatitis C related matters. HALC provides practical legal services to assist HIV positive people with matters directly affected by or affecting their HIV status such as housing issues, Centrelink issues, debt, superannuation early release, immigration, discrimination, privacy and end of life planning.

Attachment D

People with HIV in NSW

In 2010, the total number of people diagnosed with HIV in Australia was estimated to be 20,956. 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.

HIV Antibody testing

25.1% tested because they became ill, 16.9% tested as part of a routine health screening, 10.4% tested because they were a member of a risk group, 12.3% were tested because of a particular risk episode³.

HIV-related other health conditions

46.1% indicated that they had a major health condition other than HIV/AIDS. The most common health conditions reported were hepatitis C (12.7%), prescribed medication for a mental health condition in the last six months (27% for depression and 28.6% for anxiety)⁴.

¹ Mirror provisions are included in the Public Health Act (2010) NSW, Section 56 (3). This Act is yet to commence.

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

³ Grierson 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, Health, HIV Antibody testing, executive summary, pVIII

⁴ Ibid, Executive Summary, pIX