



SUBMISSION

eHealth Record

Privacy Blueprint for the Individual Electronic Health Record

We thank the National E-Health Transition Authority Ltd (NEHTA) for the opportunity to provide comment on the consultation to the Privacy Blueprint for the Individual Electronic Health Record.

The *Private Mental Health Consumer Carer Network (Australia)* (hereafter Network) represents Australians who have private health insurance and/or who receive their treatment and care, and those that care for them, from private sector settings for their *mental illnesses or disorders*. As our title implies, the Network is the authoritative voice for consumers and carers of private mental health settings.

The Network is committed to working with Governments and would be pleased to work with NEHTA in addressing the needs of people with a mental illness. Mental health brings with it many challenges. As a consumer and carer organisation we are in a unique position to provide direct lived experiences and would welcome the opportunity to engage in further consultations, either independently or with other relevant organisations.

Introduction

We note with concern from *Appendix F: IEHR Privacy Roundtable Participants* that key advocacy mental health organisations representing consumers and carers such as our Network have not been involved in formal discussions. We note from that list that Carers Australia and Consumers Health Forum Australia are presumably representing health consumers and carers but neither of these organisations have a single or strong focus on mental health. We see Black Dog Institute has been included but again, this organisation has a focus mainly on depression. We do note coincidentally that the Australian Federation of AIDS Organisations is represented. Along with mental illness, aids is also an area where discrimination is still alive and well and with these particular diagnoses confidentiality, choice as to whom information is shared, collection and dissemination is critical.

Even within the two areas of aids and mental illness there are however unique differences and issues which face people with a mental illness. One is the capacity to give informed consent, understand what is being consented to and the capacity of individuals to choose to keep this information to certain health informants is essential.

The Network does understand that not every organisation in Australia can be included in key face to face consultations, but we urge NEHTA to reconsider the list of participants and include our Network in all future consultations as a key consumer and carer mental health advocacy organisation to bring these important issues before you.

In reading through the document a number of key issues have emerged for the Network, most importantly the nature of the mental illnesses and disorders of the people that we represent.

Key issues for NEHTA to consider

First consultation question box

The Network is supportive of the concept of an *Individual Electronic Healthcare Record (IEHR)* but wish to draw NEHTA's attention to the following key issues.

1. The nature of mental illness is quite unique. The Network draws attention to the distinct hierarchy of health even with the area of illness. Mental illness is the most stigmatised and least understood health condition/disability and there are particular challenges to people with mental illness.
2. Legal issues impact on us. **At times**, we can lose the right to decide to, or not to, take medications and under a *Community Treatment Order/ Involuntary Treatment Order*, treatment is forced upon them often via depot injections. If people do not voluntarily attend a mental health service for medications, health professionals seek them out in their place of residence and require them to comply.
3. People disabled with a mental illness **can at times**, lose the right to attend to their own finances with Guardianship/Trustee Boards, determining under an *Administrative Order* who will act on their behalf, and what they will do with their monies.

What the Network is drawing attention to here is that some people do at times during an episode of mental illness, lose the right to choose confidentiality and information sharing. People with a mental illness face particular issues of involuntary admissions, treatment, restraint and seclusion. Under these situations, choice is taken from them.

The Network acknowledges that in some circumstances involuntary treatment may be necessary, such as when a person is not well enough to consent to treatment, but strong safeguards must be in place.

In consultations around the IEHR there is the assumption that persons receive medical treatment to which they agree, have the choice as to whom information is shared with, how it is collected and indeed have the opportunity to 'opt in' to the establishment and content of any IEHR.

Second consultation question box

4. All future initiatives designed to raise awareness and acceptance of and IEHR must specifically address the unique difficulties and stigma associated with mental illness and provide specific education about the rights of people with mental illness. Governments through NEHTA and COAG in any implementation of the IEHR must address and continue to address this issue.
5. The Network agrees that governing frameworks for privacy in Australia including those relevant to any IEHR must contain and continue to have privacy principles legislated in statutes, contained in administrative instructions or government-approved standards across all Australian jurisdictions. These must encompass how health information is collected, used, accessed, shared and disseminated. These must be as relevant to all private providers including private hospitals as they would be for public sector services. We draw attention to the National Privacy Principles and the Privacy Act which very much govern the private health sector, but have lesser relevance to public sector settings where jurisdictional regulations broadly apply.

6. The Network supports a national approach in offering all Australians the choice to access their own health information where, when and as they need it.
7. The Network supports the application of selected portions of an IEHR to contain test results, prescriptions, current medications, allergies and alerts, procedure history etc We do however have some reservations around hospital discharge summaries specifically from mental health facilities as we believe this could have some future bias in the care received for other medical conditions. We believe the key to this however is that disclosure is to an authorised healthcare provider to **whom the individual gives permission**.
8. We need to reinforce our concerns by advising that when mental health consumers are in the health sector outside of mental health, we know from their many experiences that health professionals just do not understand the nature of mental illness or the use, administration or side effects of psychotropic medications.

Third consultation question box

The differences between an 'authorised representative' versus a 'nominated representative'

9. Again the Network draws attention to the unique nature of mental illness. People can have acute episodes within the chronicity of their mental illness. This means that at times people can provide informed consent and that a Carer/Guardian/Trustee is not deemed necessary for all decisions. However, at times because of the illness, a carer etc must make decisions on a person's behalf. This then confuses the issue. It is not as clear cut as it would be for a very disabled person with say intellectual difficulties who will be in this way for life. The person with a mental illness has the capacity to withdraw from these types of directives.
10. Most people with a mental illness do not have a Power of Attorney, Enduring Power of Guardianship. Mostly, the best that is created for this area is an *Advance Directive* which sets out a preferred action list. This in most jurisdictions is not a legal document and unenforceable at law.

Clarification of this aspect by NEHTA is required.

Fourth consultation question box

For uptake by people with a mental illness diagnosis to have confidence in voluntarily signing up to any IEHR, the Network supports and believes the following are crucial.

11. The IEHR Service maintaining the privacy of an individual's data using a number of different mechanisms for authentication, access control, encryption, audit and complaint process.
12. The data base Administrator has clearly articulated safeguards as to the storage of the electronic information.
13. Privacy analysis is undertaken as an ongoing process.
14. All provider agreements are underpinned by a supporting regulatory framework.
15. In regard to critical situations, all 'need to know' access will be audited.

16. An audit trail exists to track all access, when, by whom and for what purpose.
17. There is a rigorous complaints process and dispute resolution process overseen by an *independent* entity such as the Privacy Commission provided it has the **powers to made determinations**.
18. All health care providers who could have access to the IEHR are authorised, credentialed and registered. We have some concerns in relation to overseas trained practitioners and authentication or re-registration via Australian medical credentialing requirements.

Two KEY issues of critical importance

The Network believes that two key critical issues exist, namely:

1. Sensitivity labels – Privileged Care

Whilst this issue has been addressed in a number of sections within the document, there is still some discussion as to whether this function can be incorporated within any IEHR. The Network considers it crucial to the people that we represent that not only is it appropriate, it is crucial to have sensitivity labels with different levels of access for healthcare providers.

We do not consider there is sufficient protection in any IEHR, whether this is opt in plus the ability to withhold information, to obviate the need for the sensitivity label. Many of us would want to have an IEHR for all the benefits this would provide, but need to be very assured that any information about our mental illness would be quarantined if that was determined by us.

We have outlined previously all the reasons why this function is essential.

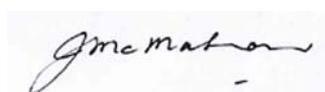
2. Potential Third Party Access

Only brief mention has been made about potential access by third parties most particularly insurance companies and courts. We would require stringent safeguards and assurances that protect all Australians from this type of access. We have grave concerns around potential employers, internet vulnerabilities and many other areas.

We note that NEHTA has been asked to consult further on these issues. As the recognised peak consumer and carer advocacy body, the Network formally requests that we be included as a key stakeholder in any and all consultations particularly around these and further issues.

We are in a position to provide information, informed advice and commentary to NEHTA and Governments.

The Network has been pleased to provide this Submission. Should you have any queries relating to any aspect of this Submission, please contact the undersigned.



Ms. Janne McMahon OAM
Independent Chair
8 August 2008