



POLICY STATEMENT 4: HEALTH INFORMATION PRIVACY AND SECURITY

Background:

Privacy of sensitive health information is a basic right for all Australians, but is of particular concern to mental health consumers. Mental health problems and disorders remain a source of stigma to many people and can be discriminated against by our society. A mental health consumer's health information is highly sensitive and any disclosure can, and indeed often does, result in discriminatory practices. If mental health consumers do not feel confident that their information will be kept secure, they may fail to disclose critical information to health professionals in other medical areas, thereby increasing the risk of possible harm to themselves or others.

The particular circumstances of mental health treatment must be considered in all initiatives relating to patient health data. Psychiatry and psychology and to a lesser extent those services offered by allied health practitioners have a number of unique and different challenges which differentiate these medical specialties from others. The main difference is the development of an ongoing trusting therapeutic relationship between the psychiatrist/psychologist and the patient and the disclosure of sensitive personal information. Unlike other fields of medicine, mental health has less specific medical tests to determine and substantiate a diagnosis, with psychiatric diagnoses being made based upon mental investigations and thorough note taking. In general, this forms the main basis of the clinical records and the privacy of these records is of particular importance.

Individual electronic health records (IEHR):

Lived Experience Australia supports a national approach in offering all Australians the choice to access their own health information where, when and as they need it.

In simple terms, the public holds a general assumption that persons receive medical treatment to which they have agreed, believe they have the choice as to whom information is shared with and how it is collected. Further, they have the opportunity to 'opt in' to the establishment and content of any individual electronic health record.

However, during an episode of mental illness, many mental health patients can lose the right to choose to keep their mental health information confidential with information-sharing between mental health clinicians being normal practice following instances of involuntary admissions, treatment, restraint and seclusion.



All future initiatives designed to raise awareness and acceptance of electronic health records must specifically address the particular discrimination and stigma associated with mental illness and provide specific education to the custodians of the information about the rights of people with mental illness. Particular protection and reassurance about the security of information is necessary for people with mental illnesses.

The robustness of the IT systems supporting the IEHR are of particular concern, and measures need to be in place to ensure that there are clear System Administrator rules and responsibilities and audit trails of access to the system including an individual's electronic health record.

Lived Experience Australia supports the application of selected portions of an IEHR to contain test results, prescriptions, current medications, allergies and alerts, procedure history etc. However Lived Experience Australia has 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. It would be considered appropriate for the release/disclosure of sensitive data be available only to an authorised healthcare provider to whom the individual gives permission. When mental health consumers are in the health sector outside of mental health, health professionals have sometimes highlighted or demonstrated a lack of understanding of the nature of mental illness or the use, administration and/or side effects of psychotropic medications.

Lived Experience Australia considers it crucial to have sensitivity labels with different levels of access for healthcare providers on any individual electronic health records. Many mental health consumers would want to have an IEHR for all the benefits this would provide, but need to be very assured that any information about their mental illness would be quarantined as of right.

Legislative separation of Medicare and PBS data:

Lived Experience Australia believes that the Medicare and Pharmaceutical Benefits Scheme (PBS) databases should continue to be mandated by legislation to remain separate. If the databases were able to be linked, then information could be combined that would reveal a picture and critical information about an individual's mental illness.

When a consumer presents an authorised healthcare provider's account for a rebate following a visit, it is not possible to identify an individual's specific medical condition from the Medicare claims data or from PBS claims information data. This is not the case for mental health consumers.

General Medicare claims data indicates visits to a health provider but does not identify the medical condition however, *under Medicare Benefits Schedule Item Number 319*, the diagnosis of mental health consumers, who receive intensive long-term psychotherapy treatment from highly trained psychotherapists, is provided to the Health Insurance



Commission. This is particularly sensitive mental health information, identifying a medical treatment which is not required for other diagnoses or conditions.

Similarly, although it would not usually be possible to accurately determine an individual's precise medical condition from PBS claims information data, the authorisation for the provision of particular psychotropic medications, or particular doses of medication, is required to record a diagnosis for that medication to be processed under the PBS.

Policy:

1. Lived Experience Australia believes that in relation to individual electronic health records (IEHR):

- Consumers should have the right to quarantine any selected information on an IEHR, to allow control over information which could potentially result in some kind of discriminatory practice.
- That sensitivity labels allowing different levels of access to information should be part of an IEHR.
- That priority be given to the security of database IT systems for the IEHR, including Systems Administration and audit trails of access both to the system itself and individual health records.
- That the IEHR include capacity for carers to access consumer health records with consumer permission ie. as part of an Advance Directive.

2. Lived Experience Australia also believes that the Medicare and PBS databases must remain unlinked.

Policy approved: June, 2010