

PERSONAL INFORMATION AND PRIVACY PRINCIPLES

Safeguarding the privacy of personal information and the right of users to access their own information are essential components of a health and community service system and need to be protected at all times. These two principles, privacy and access, reflect the practice of many, but not all, health service and community service providers today.

How would you like to find out that your personal information had been made available to a third party for other than a health or community service related purpose, you were not made aware of the release of the information and your permission was not sought?

My position on this is quite clear. The provision of personal information by a provider to a third party in a context not directly related to the provision of a health service or community service, and without the consent of the user, involves a fundamental breach of duty by that provider. Providers should not allow a third party access to personal information without the consent of the user, or as allowed by law.

I believe this position is also supported by:

- The authority of *Breen v Williams* [1996] 186 CLR 71: This decision established that the provider owned the medical records. However, it did not suggest the owner had a right to use that information in any way that he or she determined appropriate. To the contrary, all members of the High Court referred to the distinction between ownership of medical records and the right to access them. They spoke about the equitable obligation or duty of confidentiality which may be owed to an individual to whom information contained in the record relates. In essence, an individual's personal health information should not, in other than exceptional circumstances, be used for purposes other than that for which it was collected: to inform the provision of health services. The distinction between ownership and the right to deny access, and the use of information in records, is often misunderstood.
- Section 12(2) of the Evidence Act, which states "A medical practitioner shall not, without the consent of his patient, divulge in any civil proceeding (unless the sanity of the patient is the matter in dispute) any communication made to him in his professional character by the patient, and necessary to enable him to prescribe or act for the patient".
- The general common law duty to maintain patient confidentiality, subject to various exceptions. See *Furniss v Fitchett* [1958] NZLR and *W v Edgell* [1989] 2 WLR 689.
- Medical practitioners and other health providers being obliged by their codes of ethics to maintain patient confidentiality.
- The existence of other Codes, such as Territory Health Service's Information Privacy Code of Conduct, which regulate the use of private information in the public health and community service system.

The proposition is very simple: a service user and a treating team should have access to all information the user's health record, unless there is good reason against such action. The collection and flow of detailed personal information between service providers is often essential for the safe and effective treatment of users. The flow of personal information to those not involved in the provision of the service however should be controlled by the user.

There are a number of actions being taken, the results of which will have a significant impact on the future handling of personal information throughout the Northern Territory. These are:

- The review by the Commonwealth of the Privacy Principles under the Privacy Act 1998: In conjunction with this review it has been proposed to extend the Privacy Principles to encapsulate personal health information held in the private health sector.
- The Proposal for the Northern Territory Government to enact its own privacy legislation: Reference has been made by the Northern Territory Government to an intention to introduce "privacy type" legislation. I am informed that the Northern Territory's privacy legislation will be based around the National Principles for Fair Handling of Personal Information. This legislation will support the development of approved Codes of Practice so that a public sector organisation is able to tailor its obligations with respect to the privacy principles.

- The review by Territory Health Services of their Information Privacy Code of Conduct: This review aims to simplify the existing Code and ensure that it is consistent with the proposed extension of the National Privacy Principles to cover personal health information held by private providers and the proposed Northern Territory privacy legislation.

The policies and principles governing these issues should be effective and transparent, not in conflict with each other, and strictly committed to patient confidentiality and privacy. They need to address issues such as:

- Service users having control over access in order to allow the transfer of personal information from one provider to another.
- Multi-provider consent which will enable the transfer of information to members of a treating team for an episode of care. It may otherwise be impractical to obtain consent for them all to share the information.
- The requirement for unambiguous and consistent practices in the alteration and destruction of personal information recorded about an individual's care and treatment.
- Processes relating to access. For example:
 - specifying relevant exemptions;
 - having special arrangements when the provision of clinical information might be harmful if misinterpreted;
 - reviewing decisions to exempt information;
 - accessing records by next of kin or guardians of people who are deceased or legally incompetent; and
 - accessing records obtained by or brought into being by insurance companies and others.
- Ensuring the quality of information can be assured, including opportunities for health care consumers to review and correct the information.
- Transfer of information when users change practitioners, or there is a closure or transfer of practice.
- Ensuring verbal breaches of privacy are adequately handled.
- Ability for users to make complaints relating to breaches of privacy to a single authority

The difficulty is that any principles must ultimately apply and be consistent across the health service and community service sectors. Unless regulation of these principles come under one umbrella, I believe this will be a nigh on impossible task. For example, the health industry alone comprises many different agencies and organisations, numerous professions and occupations and many specialities. The worst possible outcome would therefore be the creation of scores of different codes, each administered by a different organisation. The complexities for users who have concerns about information which has been shared amongst many service providers or who wish to obtain access to information held by many organisations, are obvious.

There is a need therefore to establish, through legislation or a Code, privacy and confidentiality principles which achieve the following goals:

- they apply to personal information collected and held in the health service and community service sectors; and
- they provide consumers with an enforceable right to information recorded about their care and treatment.

The Australian Capital Territory has achieved these goals through the introduction of the Health Records (Privacy and Access) Act 1997 and Victoria are in the process of framing a Health Records Bill. The Code of Health and Community Rights and Responsibilities, currently being developed by the Commission, will include principles relating to privacy and confidentiality of personal information and will be applicable across the health service and community service sectors.

Principle 4 of the draft Code relates to Access to Personal Information and Principle 5 to Confidentiality and Privacy. These Principles currently read as follows:

Principle Four: Access to Personal Information

1. Users of health services and community services have a right to
 - a) information about their health and community care. However, users of health and community services do not have an automatic right of access to their care and treatment records; and
 - b) where third parties are seeking access to personal information held by providers, formal procedures being instituted which ensure users:
 - are informed of the request for access; and
 - consent or refuse consent to access, unless legislation provides otherwise.

Principle Five: Confidentiality and Privacy

1. Providers of health services and community services have a responsibility to respect and protect the confidentiality and privacy of service users and to:
 - a) ensure that personal information held by them is not made available to a third party:
 - if such information is not directly related to, or required for, the provision of a health service or community service to the user; or
 - without the consent of the user; unless legislative provisions require them to do so.
 - b) provide users with information, from their records, about their care and treatment. The provider may restrict access to such information if:
 - there are legislative provisions which support such action; or
 - the provider has reasonable grounds to consider access to the information would be prejudicial to the physical or mental health of the user.
 - c) provide appropriate surroundings to enable private and confidential consultations and discussions to take place;
 - d) have policies and procedures in place requiring all staff to protect confidentiality, and ensure all staff are aware of these;
 - e) ensure the service user's personal information is stored in such a way as to ensure the user's privacy and confidentiality is protected; and
 - f) communicate appropriately, in a manner which respects the requirements of confidentiality, with other providers involved in the user's care and treatment.
2. Both users and providers of health services and community services have a responsibility to recognise that :
 - a) legislative provisions may require providers to disclose information given to them by users of health services and community services; and
 - b) disclosure of information to other health service or community service providers may be essential for the provision to good care and treatment. Providers have a responsibility to obtain the user's consent, prior to such disclosure taking place. This may take the form of consent to share information amongst a care or treatment team.
3. Users of health services and community services have a responsibility to respect the confidentiality requirements that apply to providers.

It is fundamental to the relationship between the provider and the user of a health service or a community service that any information obtained and recorded will be kept confidential, used for the purpose for which it was provided and not disclosed to unauthorised persons. To fail to adhere strictly to this principle is likely to erode the special relationship and trust that must necessarily exist between the provider and the user of the service.

Any complaint received by the Commission relating to a provider allowing a third party access to a user's personal information, without the consent of the user or unless allowed by law, will be assessed by the Commission as a fundamental breach by the provider of his or her duty to the user.