

PROTECTING THE PRIVACY OF HEALTH INFORMATION IN THE NORTHERN TERRITORY

The Minister for Health and Community Services, the Hon Jane Aagaard, has released a public Discussion Paper, Protecting the Privacy of Health Information in the Northern Territory.

This Discussion Paper was released to promote consultation about the need for health-specific privacy legislation to cover both the public and private health sectors in the Northern Territory.

The current privacy framework that applies to health information in the Northern Territory is complex and made up of the following elements:

- health related legislation, with specific provisions about confidentiality or that otherwise restrict the collection, use or disclosure of particular health related information;
- common law medical confidentiality obligations applying to practitioner-patient relationship;
- various codes of ethics;
- the Department of Health and Community Services (DHCS) Information Privacy Code of Conduct, which applies to all health service providers in the public sector and all contractors providing services to and on behalf of DHCS;
- various laws requiring the mandatory reporting of information by health practitioners, including public health, community welfare and motor vehicle legislation;
- the Commonwealth Privacy Act 1988 which applies to health information in the private sector; and
- when the proposed Northern Territory Information Bill is introduced, it will provide a privacy framework for health information in the public sector.

Personal health information is sensitive, private and fundamentally personal in its nature. It is therefore absolutely essential that it be protected. The Discussion Paper proposes the development of a Health Privacy and Records Bill to do just that in one piece of legislation for both the public and private sectors. I am very supportive of its development and introduction.

The major test for this proposed Bill will be whether it strikes the right balance between realising the health care benefits that accrue from the effective use of new health information and communications technologies to deliver health care improvements and efficiencies on the one hand, and devising methods that protect the privacy of the health information used in those systems on the other .

A further test, and of great importance to individuals, will be whether the proposed Bill provides them with an enforceable right of access to their records. This is something they do not have at the moment.

The Northern Territory is not the first to propose health privacy and records legislation. Both the ACT and Victoria have successfully introduced such legislation and therefore the proposed NT legislation can build on what those jurisdictions have already put into place.

The Discussion Paper proposes that the health privacy and records regime will achieve the following:

- The protection of the privacy of an individual's health information in both the public and private sectors in the Northern Territory by reference to a nationally accepted benchmark, the National Health Privacy Principles (NHPPs).
- The establishment of a right for individuals to access their own health information.
- Conferring jurisdiction on the Health and Community Services Complaints Commission to oversee the health privacy regime and to handle and resolve complaints effectively and quickly .

In addition to the above, in my 1999/2000 Annual Report I stated that any efficient and effective health privacy and records regime would need to address the following issues:

- 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.

Although I am satisfied that the proposed Bill will go a long way to achieve the objectives above, I offer the following comments after reviewing the Discussion Paper.

OVERSEEING THE HANDLING OF COMPLAINTS AND RESOLUTION OF DISPUTES

I noted that the Health and Community Services Complaints Commission is proposed as being responsible for overseeing the legislative scheme, for handling complaints and resolving disputes under the proposed Bill.

As the Commission already has responsibility for receiving, considering, investigating, conciliating and resolving complaints against public and private health service providers, it would be an efficient and effective use of their considerable experience and expertise to have them undertake these additional tasks.

As stated in the Discussion Paper it would be necessary that the following functions be added to those of the Health and Community Services Complaints Commission:

- To promote an understanding and acceptance of the Health privacy Principles (HPPs) and the objectives of the legislation.
- To receive complaints about the privacy practices of organisations.
- To investigate, conciliate and make decisions about privacy complaints.
- To issue guidelines for the purposes of the HPPs.
- To consider and, if appropriate, approve Codes of Practice.
- To conduct or commission audits of records of health information held by organisations to ascertain whether the information is being or has been dealt with in conformity with the legislation and the HPPs.
- To undertake educational programs relating to health privacy on the Commission's behalf or in conjunction with other bodies whose functions concern the protection of the privacy of personal information.
- To publish reports and recommendations relating to health information privacy.
- To undertake any other functions under the legislation or that are referred to the Minister.

I note that the Discussion Paper emphasises the need for meaningful, low cost and timely complaints handling and dispute resolution similar to legislation in both the ACT and Victoria. The emphasis on alternative dispute resolution processes such as mediation is also very consistent with the principles contained in the Health and Community Services Complaints Act.

JURISDICTION

It is agreed that the health services' environment in the NT is unique, however, regardless of the environment all Territorians (and Australians for this matter) are entitled to protection and privacy of their personal medical records, whether provided by a public or private provider. Accordingly, I concur with the concept that the proposed Bill cover all providers, rather than having private health providers covered by the Commonwealth Privacy Act 1998 and the public providers potentially covered by the draft NT Information Bill. The jurisdiction of the proposed Bill as stated in the Discussion paper is also consistent with the Health and Community Services Complaint Act 1998 - which deals with both private and public health providers.

DEFINITIONS

The definitions "health information" and "health service" should be drafted to allow the widest interpretation possible to cover all medical information, wherever it is collected, stored, processed, transferred or used, no matter the form.

Legal coverage should not be limited to only medical information collected in the provision of health care but should include information collected for financial, educational, employment, marketing and other reasons" .

"Health" should be defined in a holistic manner relating to the spiritual, emotional and physical well being of a person. Such a definition is particularly important if the legislation is to have meaning for all Territorians, particularly Aboriginal people who constitute 28% of our population.

APPLICATION OF THE PROPOSED HEALTH PRIVACY AND RECORDS BILL

It is important that the proposed Bill apply to all organisations, persons, incorporated entities, partnerships, trusts, and unincorporated associations in the Northern Territory, whether or not they are involved or provide a health service. All medical information pertaining to a person within the NT must be protected by the legislation.

PUBLIC SECTOR OUTSOURCING

I note it is proposed that organisations who provide contracted services to the NT Government, through any outsourcing arrangements, will be bound by the legislation to the same extent as any public sector organisation. In this event criminal and civil sanctions should be included in the legislation to enable "substantial criminal and civil fines for actual or attempted unauthorised access, disclosure, or use of medical information. Individuals should be able to enforce rights and obtain damages and related costs in civil court. An independent agency [such as the Health and Community Services Complaints Commission] should be created to conduct oversight and enforce the provisions ..."

ACCESS BY THE INDIVIDUAL

The Discussion Paper contemplates that the proposed Bill will provide restrictive access rights of an individual. Although the Discussion Paper proposes that a request by an individual for access to their health information may be made orally, in practice the organisation or provider will force them to put their request in writing. In doing so the individual will be required to specify the details of the information required and the manner in which it is sought. The organisation or provider does not have to provide the information until the request is put in writing and once this is done, has 30 days to respond.

Providing the individual provides adequate information there should be no justification for not accepting an oral request. This is particularly important in the Territory where a large majority of our population speak English as a second or third language. We should make it simple, not difficult, for people to request their health information.

"A patient should have full access to all personally identifiable medical records. No records should be kept secret. Record keepers should be required to notify patients that they maintain records. Patients should have the ability to correct or remove any inaccurate, irrelevant or out-of-date information. Any card-based data system must allow consumer access to all personal information contained on that card".

EXERCISING THE ACCESS RIGHT

The access rights envisioned for the proposed Bill require more flexibility. The Discussion Paper proposes that if a person is entitled to access their medical information then a suitably qualified person (if not the person who obtained / recorded / collated the information / data) should explain it so that it is understandable. That is, the information should be communicated in a form that is readily intelligible.

SECURITY

Any proposed legislation should ensure that the creation of electronic databases of unified clinical records without the consent of the patient be prohibited. Psychiatric records should not be included in any system of electronic records. Information should be protected by the best electronic security. Records in storage or transit should be encrypted. Audit trails should track access to individual files, access should be limited to relevant data, and the number used as a patient record identifier should not be used elsewhere or for purposes other than for tracking an individual's medical records within the context of delivering health services to the individual.

CODE OF CONDUCT

I strongly support recent legislative developments (at Federal and State level, including the NT's draft Information Bill) requiring that privacy be dealt with in a more rigorous and comprehensive way and beyond just the public sector. I also endorse the proposition that any proposed health privacy code of practice be approved by the Commissioner for Health and Community Services Complaints to ensure compliance with the object and purpose of the proposed Bill and it is not contrary to the public interest.

AUTHORISATIONS / COMPLIANCE NOTICES / OVERSIGHT OF LEGISLATION

There may be times when it is appropriate for a departure from the privacy principles to be permitted in a 'one-off' situation. In such circumstances I agree that deviations should require oversight and approval and that the Commissioner for Health and Community Services Complaints is the appropriate person to authorise such. I also support the proposition that the Commissioner be empowered to oversee compliance with the proposed Bill and conduct audits and issue compliance notices.