

Procedures for The College of Nursing Human Research Ethics Committee in conjunction with the Privacy Act, 1988

Subsequent to advice from the Office of the Privacy Commissioner and Ms Josephine Holland of Blake Dawson and Waldron Solicitors, as well as careful perusal of the Privacy Act, 1988, The National Privacy Principles, and the Office of the Federal Privacy Commission's Information Sheet 9 – 2001 Handling Health Information for Research Management the following procedures have been identified to assist The College of Nursing Human Research Ethics Committee in their deliberations relating to the conduct of research involving students (or members) of The College of Nursing.

The sections of the documents as indicated in Appendix 1 are considered particularly pertinent to researchers wishing to conduct research using students (or members) of The College of Nursing, as well as to the The College of Nursing Human Research Ethics Committee who consider research proposals relating to this. These documents form the basis on which the following procedures relating to the use or disclosure of information gained by The College of Nursing from students enrolling in a course conducted by that College, or from members of the College, have been developed.

Sentinel Points:

- The information being used or disclosed must be directly related to the primary purpose for which it was collected;
- The individual providing the information could reasonably expect the organisation to use or disclose the information for that purpose. (Information Sheet 9 – 2001 Handling Health Information for Research and Management).

In relation to research involving students of The College of Nursing, researchers should provide evidence in their proposal that the above procedures have been considered and a rationale relating to their application to the research in question provided.

A further point for consideration by both The College of Nursing Human Research Ethics Committee and researchers in the context of attention to ethical issues in research relates to NPP 2.1(b) – Secondary use and disclosure with consent. Both parties should ensure their familiarity with, and attention to this section of the National Privacy Principles, and ensure that compliance has been met within the proposed research.

Procedures for NPP2 - Use and Disclosure

NPP 2.1(a) Primary and related purposes

Primary Purpose

Determining the primary purpose of collection should always be possible. Where an organisation collects personal information directly from the individual the context in which the individual gives the information to the organisation will help identify the primary purpose of collection. When an individual provides and an organisation collects personal information, they almost always do so for a particular purpose – for example, to buy or sell a particular product or receive a service. This is the primary purpose of collection even if the organisation has some additional purposes in mind.

How broadly an organisation can describe the primary purpose will need to be determined on a case-by-case basis and it will depend on the circumstances.

Where an organisation collects personal information indirectly a guide to its primary purpose of collection could be what the organisation does with the information soon after it first receives it.

Secondary Purpose

Related and directly related purposes within reasonable expectations

To be related the secondary purpose must be something that arises in the context of the primary purpose.

If personal information is sensitive information the use or disclosure must be directly related to the primary purpose of collection. This means that there must be a stronger connection between the use or disclosure and the primary purpose for collection.

Individual's reasonable expectations

The test for what the individual would 'reasonably expect' would be applied from the point of view of what an individual with no special knowledge of the industry or activity involved would expect.

The NPPs are not intended to prevent personal information about individuals acting in a business capacity from being exchanged in the normal course of a business. In these circumstances, ordinarily it is likely to be within individual's reasonable expects that information about them will be used and disclosed for generally accepted business purposes. For example, exchange of business cards and use of them for later business contacts would ordinarily be consistent with the NPP.

NPP 2.1(b) Secondary use and disclosure with consent

This allows an organisation to use or disclose personal information for a secondary purpose if it has the individual's consent. Consent to the use or disclosure can be express or implied. Implied consent arises where consent may reasonably be inferred in the circumstances from the conduct of the individual and the organisation. For example, it may be possible to infer consent from the individual's failure to opt out provided that the option to opt out was a clearly and prominently presented and easy to take up. If the organisation's use of disclosure has serious consequences for the individual, the organisation would have to be able to show that the individual could have been expected to understand what was going to happen to information about them and gave their consent. In such situations it would ordinarily be more appropriate for the organisation to seek express consent.

NB: The Tips for compliance related to this section.

Information Sheet 9 -2001 Handling Health Information for Research and Management

Using or disclosing health information

Using or disclosing health information for health service management activities.

While NPP 10 specifically addresses the collection of health information for the management, funding and monitoring of a health service, the use and disclosure principle, NPP2, does not. Identified information may be used or disclosed for managing, funding or monitoring a health service in limited circumstances. It may be used or disclosed for these purposes where:

- *the person has consented to the use or disclosure (NPP 2.1(b));*
- *the information is being used or disclosed for the same (primary) purpose for which the information was collected (NPP2.1);*
- *the information is being used or disclosed for a purpose directly related to the primary purpose for which the information was collected and the person would reasonably expect the organisation to use or disclose the information for that purpose (NPP 2.1(a); or,*
- *another exception to NPP 2 applies.*