



COMMONWEALTH PRIVACY AMENDMENT (PRIVATE SECTOR) ACT 2000

INFORMATION SHEET 1 – INFORMED CONSENT

What is informed consent?

If a health provider has the consent of an individual to collect, use or disclose his or her health information, then the health provider is free to work with the information *within the limits* of that consent. Consent is relevant for health information in all its forms, including electronic records and data. Valid, or informed, consent requires that the individual knows and understands how the information collected will be used and disclosed. In relation to the Act, consent to collect information and consent to use and disclose amount to the same thing. It is important to note that consent to collect information does not imply consent to treatment.

There are three key elements involved in seeking consent. Unless all the elements are addressed, the individual cannot be considered to be providing informed consent. The key elements are:

- 1) consent must be provided voluntarily;
- 2) the individual must be adequately informed; and
- 3) the individual must have capacity to provide and communicate their consent.

As a general rule, if a health provider is in doubt about whether an individual is giving their consent or not, it is preferable to seek the individual's express consent. In emergencies, the National Privacy Principles (NPPs) recognise that it may not be appropriate to seek consent from an individual about privacy issues as their health needs take immediate priority.

Express consent versus implied consent

Express consent refers to consent that is clearly and unmistakably stated, either in writing or orally. As an individual's wishes may change over time, particularly in relation to long term health issues, a GP may need to check that the consent remains up to date and relevant to the current situation. There are, however, situations where a GP may reasonably rely on implied consent to handle health information in certain ways. For example, it is generally regarded that implied consent has been given to collect information for certain purposes if that information is disclosed during a consultation. Similarly, if a GP collects a specimen for pathology testing then it is reasonable to consider the individual is giving implied consent to necessary information being passed to the pathology laboratory.

In some situations it is preferable to obtain confirmation of consent in writing, particularly when it involves non-routine uses or disclosures of information (eg: research). Where it is not practical to obtain written consent, a GP may decide instead to make notes in the individual's file regarding whether consent was given or refused.

Consent on behalf of an individual

An individual may not be able to give consent because they do not have the capacity (ie: they are too young, are cognitively or intellectually impaired or are unconscious or in distress). In such cases, the NPPs allow for the disclosure of an individual's health information to a person who is 'responsible' for them to ensure appropriate treatment and care or for compassionate reasons.

Health providers must not assume that a person with a disability is necessarily incapable of giving consent to the handling of his or her personal information. Most people with disabilities are able to make their own privacy decisions and have the legal right to do so. Health providers will need to ensure that privacy issues are discussed with the individual in a way that is appropriate to their ability to understand and comprehend the information.

Many individuals who have a guardian or other person assisting them with certain matters may still have capacity to provide consent in other instances. Even if an individual lacks *legal* capacity, they should be involved as far as is practical, in decision-making processes that affect them.

In some circumstances it may be appropriate for a GP or other health provider to contact their local Guardianship Tribunal or Board for further advice regarding this issue.

Who may give consent on behalf of an individual?

When consent is required and an individual lacks capacity, a GP or other health service provider can obtain consent from:

- 1) a guardian;
- 2) someone with an enduring power of attorney that can be used in relation to an individual's health;
- 3) a person recognised by other laws, such as a 'person responsible' under the NSW Guardianship Act; or
- 4) a person who has been nominated in writing by the individual while they were capable of giving consent. The health provider must be satisfied that there are no reasons to believe that following the individual's written request would be to act against his or her current wishes.

Where there is no one who can act on an individual's behalf

If there is no one with legal authority, or no one nominated in writing by the individual, the health provider will need to make a professional judgement about who is most appropriate to act on the individual's behalf, taking into account the individual's interests. In many situations where there is no-one at all available to act for an individual, the health provider may still make decisions about appropriate handling of the individual's health information, provided this occurs in accordance with current laws and practices.

Children and young people

The Privacy Act does not specify an age after which an individual can make their own privacy decisions. NSW Health regards individuals who are over 14 years of age as being sufficiently mature to be able to provide informed consent.

In general, where the young person is capable of providing consent, then he or she should be approached for consent not his or her parent. It is for the GP to make a professional judgement whether a young person is capable of providing consent in a particular situation.

Where the child or young person is not of sufficient age and maturity to give informed consent then a parent (or guardian) may act on behalf of a child or young person.

'Opting Out'

It is questionable whether implied consent can be inferred from a failure to "opt-out", or object to, a particular way of handling an individual's health information, because it is not clear an individual had the relevant knowledge to exercise the necessary informed choice (eg: where a box is included on a form and the individual must tick the box if they *do not* wish their information disclosed).

When using this approach, it is essential individuals are clearly informed about the option to 'opt out' and that this option is prominently presented and easy to adopt.

Circumstances where collecting health information does not require consent

A GP or other health provider may collect health information without an individual's consent when:

- 1) the collection is necessary to provide a health service, and collection is carried out according to certain professional rules of confidentiality that are binding and issued by competent health and medical bodies (*Note: The RACGP's 'Code of Practice for the Management of Health Information in General Practice' is NOT binding on General Practitioners*);
- 2) if there is a law requiring them to collect that information (eg: notifiable diseases);
- 3) in situations where there may be a serious and imminent threat to the life or health of *any* individual (such as an emergency, in which an individual may be unconscious, or in pain or otherwise unable to provide consent, but where urgent treatment is required); or
- 4) for research or statistical purposes relating to public health or public safety (special guidelines apply).

Note: This information sheet refers to National Privacy Principle 2 and 10. For more information on the National Privacy Principles, or the Privacy Act, contact your local Division or the Alliance of NSW Divisions on 92392900.