

7 Collecting personal health information (HPPs 1–4)

Everyone who has direct contact with patients may have some role in collecting personal health information. Those not involved in direct service provision, such as admissions clerks, may also collect information.

7.1 When can you collect information? (HPP 1)

While privacy laws impose some controls over when personal health information can be collected, these will not affect the core business of NSW Health.

The laws clearly allow health services and health staff to collect personal health information for purposes relating to health care and treatment.

Health services are established under the *Health Services Act 1997*. Some of the key functions set out in that Act include:

- to provide relief to sick and injured persons through the provision of care and treatment
- to promote, protect and maintain the health of the community
- to conduct and manage public hospitals, health institutions, health services and health support services under its control
- to achieve and maintain adequate standards of patient care and services
- to ensure the efficient and economic operation of its health services and health support services and use of its resources
- to investigate and assess health needs in its area
- to plan future development of health services in its area
- to provide education and training relevant to the provision of health services
- to undertake research and development relevant to the provision of health services.

When collecting personal health information you should consider these functions. Information can only be collected if the purpose of collection is directly related to what the agency does and the collection is necessary for those purposes.

Example: Collecting details of a patient's income is unlikely to be necessary for provision of public health services. Collection of information about pensioner or veteran status may however be necessary, if this information impacts on patient entitlements.

Information cannot be collected by an “unlawful means”.

Example: Information cannot be collected through recording a conversation without a person's consent, as this would breach laws relating to listening devices in NSW.

7.2 How should information be collected? (HPP 2)

HPP 2 requires a health service to take reasonable steps to ensure:

- the information collected is **relevant to the purpose, is not excessive and is accurate, up to date and complete**, and
- collection of the information does not **unreasonably intrude** on the personal affairs of the individual.

This means that health services should be sensitive to, and take all reasonable steps to minimise, intrusion on the people from whom they collect personal health information. Particular care should be taken when it is clear the information may be personal, distressing or embarrassing to the patient concerned.

Example: Information about a mental illness is requested from a patient while sitting in the open reception area of a community health service. Other patients waiting to be seen can hear the discussion clearly, and the patient is uncomfortable. You should seek to collect the information in an environment where the potential for other people to overhear details is minimised, for example, using another room if available, or taking him aside to discuss privately.

Example: Doctors in a crowded emergency department request information from a patient who has just been brought in with a serious injury. Given the urgency of the situation, it may be appropriate for the medical staff to obtain this information, regardless of the fact that other people may overhear.

7.3 Who should information be collected from? (HPP 3)

Personal health information must be **collected from the person** it relates to, **unless it is unreasonable or impracticable** to do so.

Example: A frail but alert elderly woman is accompanied to admissions by her son. Her son requests that you address questions to him, out of his mother's hearing, as he feels this will be quicker and less distressing for her. You should not proceed in this way purely on the basis of the son's request. If the woman is able and willing to provide this information, you should obtain it from her.

If the elderly woman indicates that she wants her son to answer for her, you should try to make sure she understands and is involved.

Common examples of where it may be **unreasonable or impracticable** to collect personal health information directly from the person it concerns include:

Taking an individual or family medical history for your patient, where you require information about sibling illness or medical history to assist in making a diagnosis and providing care to your patient.

Where patient lacks capacity and that lack of capacity impairs their ability to give you necessary information, you may collect it from an authorised representative.

Where the person is seriously injured or in a coma due to an accident and cannot communicate, the necessary information can be collected from a family member, paramedic or other person who may have seen the accident.

Where the information is obtained from another health practitioner as part of a referral.

7.4 Informing individuals about what is collected (HPP 4)

7.4.1 Who do you need to inform if you have collected the information?

Generally, you should tell the person to whom the information relates what is collected, by whom, how it will be used, and their rights in relation to it.

This applies irrespective of whether the information was collected from a third party, or directly from the person concerned.

The law recognises there will be situations when it is not reasonable or appropriate to do this.

Those examples of most relevance to health services are set out below.

7.4.1.1 The person to whom the information relates lacks capacity

If the person to whom the information relates is not capable of understanding the information provided to him or her regarding the collection, security, use and disclosure of his or her personal health information, this information can be given to the person's authorised representative.

Where you need to deal with an authorised representative it is still good practice to explain the points to the person to whom the information relates in a way that is appropriate to their level of understanding. This is to enable the person to be involved in the notification process to the greatest extent possible.

7.4.1.2 The person waives their right to be told

If the person expressly waives their right to be told information regarding the collection, security, use and disclosure of his or her personal health information, HPP 4 does not need to be complied with. HPP 4 requires this consent to be an "express consent", so any such waiver should be recorded to enable later verification.

7.4.1.3 Informing a person will prejudice their interests or pose a threat

You do not need to tell someone you have collected information about them if this would pose a serious threat to life or health, prejudice the individual's interests, prejudice law enforcement or investigative activities.

Example : If you had collected information about the drug dependency of a violent spouse as part of providing advice and support to a domestic violence victim, you would not be required to tell the violent spouse you had collected the information, if it would place your patient, yourself or another person at risk

7.4.1.4 Where the information is collected from a third party

Health services do not have to inform an individual about information they have collected about them from a third party if:

- the information was collected from a third party because it was unreasonable or impractical to collect it from the individual, and it would also be unreasonable or impractical to inform the individual about the collection
- the information was collected in the process of recording a family, social or medical history, and this was necessary to provide health services to the patient
- the information is collected from an authorised representative because the health service believes that the individual is incapable of understanding the nature of the information required
- the information was initially collected by another agency or organisation and there are reasonable grounds to believe that the individual has already been informed of the necessary information by that other agency or organisation.

When information should be provided in these circumstances is governed by Statutory guidelines issued by the NSW Privacy Commissioner, Information and Privacy Commission NSW.



Further guidance

- NSW Privacy Commissioner's *Statutory guidelines on notifying a person when you have collected health information about them from someone else*, available at: www.ipc.nsw.gov.au/privacy/ipc_legislation

7.4.2 What information do individuals need to be told?

Except for the circumstances outlined above, Health Privacy Principle (HPP) 4 requires that individuals must be told certain information at the time, or as soon as practicable after, their personal health information is collected. The information that individuals must be told is:

- the **identity of the health service** collecting the information and how to contact it
- the **purposes** for which the information is collected
- **who the health service usually discloses information** of that kind to
- **other laws** that require the particular information to be collected
- an individual's right to **request access** to information held about them
- consequences, if any, **if all or part of the information is not provided**.



Further guidance

- Section 7.4.5 – Privacy Leaflet for Patients – Development
- Appendix 5 – Pro Forma Privacy Leaflet for Patients

7.4.3 When should individuals be told?

The information should, where practicable, be given to patients before, or at the same time, as the information is collected.

If it is not practicable to inform the individual at the time the information is collected the health service should do what it reasonably can to inform the individual subsequently.

7.4.4 How should individuals be told?

It is the responsibility of the agency which collects personal health information directly from the patient (or their representative), normally a health service, to inform individuals about how they can expect their personal health information to be treated.

Information can be provided in a variety of ways, including:

- 'Privacy Leaflet for Patients' (see Section 7.4.5) to be made available to all patients
- Verbal reinforcement or explanation of 'Privacy Leaflet for Patients' where necessary
- Privacy poster (see Section 7.4.6) and counter notices displayed in public areas of health services
- Information included on admission forms
- Information provided on the health service's website.

This information should be prominently displayed, readily and easily accessible to patients, in admission areas, community health reception areas, hospital wards, outpatient waiting rooms, Emergency Department waiting rooms and in all public access areas where patients receive services.

Health services should not rely only on verbal communication of this information unless the circumstances provide no alternative. If information is only provided verbally, a written note should be made in the health record to ensure a contemporaneous record is kept of the information provided.

7.4.5 Privacy Leaflet for Patients – Development

The NSW Health 'Privacy Leaflet for Patients' sets out the general information which should be provided to patients. This information must be presented in a format and in language that they can understand. The leaflet should be adapted by health services to include local health service contact details.

The proforma leaflet may be further adapted to accommodate specific services which may have additional or different information sharing needs and patient expectations to address. Examples of such services include, but are not limited to, palliative care, mental health, drug and alcohol, sexual health, genetics services, and services for young people (see Section 7.4.7 Youth-friendly privacy resources). If the service is linked to a particular Commonwealth program, or if routine reporting is required, this should also be included.

In all cases, the leaflet must cover the criteria listed in Health Privacy Principle 4 (see Section 7.4.2 What information do individuals need to be told?). It should also be sufficiently clear to allow the patient to readily assess and understand the circumstances when their information may be shared, for example, whether it is shared with a wider treating team.

Circumstances for sharing patient information to be listed in the leaflet must not extend beyond the primary, secondary and lawfully authorised purposes described in Section 11.

When adapting the pro forma privacy leaflet, health services should contact their local Privacy Contact Officer, to ensure the adaptations remain within the parameters of the Health Privacy Principles.

For copies of the local privacy leaflet or any other related enquiries, staff should liaise with their Privacy Contact Officer in the first instance.

A contact list for NSW Health Privacy Contact Officers is available via the NSW Health privacy webpage at: www.health.nsw.gov.au/patients/privacy/Pages

The pro forma leaflet is also available via this webpage and an example is also provided in Appendix 5 of this Manual.

The pro forma 'Privacy Leaflet for Patients' is available in 29 community languages via the NSW Health Privacy website, or via the Multicultural Health Communication Service website at: www.mhcs.health.nsw.gov.au/

7.4.5.1 Privacy Leaflet for Patients – Distribution

The privacy leaflet should be readily available to all patients receiving NSW Health services.

In addition, copies of the privacy leaflet should be clearly displayed and available in all hospital and community health service public waiting areas. Copies of the leaflet may also be provided at the bedside, and included in any 'Information Pack' sent to patients scheduled for admission to hospital.

Depending on the nature of the health service being provided, patients accessing a health service for the first time should be provided with the leaflet at the time of their initial consultation, accompanied with some verbal explanation as to how the individual's personal health information may be used and disclosed.



Further guidance

- Section 7.4.2 – What information do individuals need to be told?
- Section 11 – Using & disclosing personal health information (HPPs 10 & 11)
- Appendix 5 – Pro forma Privacy Leaflet for Patients

7.4.6 Privacy poster

The NSW Health Privacy Poster should be displayed in public areas, such as in Emergency Department waiting rooms, Outpatient and Community Health waiting rooms. In addition, the Privacy Poster should be displayed, where appropriate, in wards, corridors, at information points, concierge, nurse stations, and so on.

Please contact the Privacy Contact Officer for your health service for copies of the Privacy Poster.

7.4.7 Youth-friendly privacy resources

Research documented in the NSW Youth Health Policy has shown that one barrier to prevent young people accessing health services is uncertainty regarding confidentiality of health information.

Youth-friendly confidentiality resources, including a poster, pocket-sized-card, and online fact sheet, have been developed by NSW Kids and Families to inform young people (aged 12-24 years old) about the confidentiality of their health information.

Health staff are encouraged to provide all young patients with the youth-friendly privacy brochure, and to discuss any privacy concerns or questions.

The Youth-friendly confidentiality resources are available via:

- NSW Health 'Better Health Centre' via bhc@nscchhs.health.nsw.gov.au
- NSW Health Kids and Families website at: www.kidsfamilies.health.nsw.gov.au/publications/youth-friendly-confidentiality-resources/



Further guidance

- Section - 5.5.2 Minors
- Youth Health Policy 2011-2016: Healthy bodies, healthy minds, vibrant futures (PD2010_073)

