

INFORMATION SHEET 4 – COLLECTION OF INFORMATION

Quick Reference

This information is primarily intended for Executive Officers/Managers, Administrative Staff and Health Practitioners

Explain why the information is needed and how it will be handled

Collect from another person only when it is not reasonably practicable to obtain consent from the consumer themselves

Tell the consumer about this and verify the information as soon as possible afterwards

Collect only information that is necessary for the specific service to the consumer

If collecting additional information, seek the consumer's consent

Collect in a manner that is sensitive and appropriate to the person's circumstances

INTRODUCTION

Health Privacy Principle (HPP) 1 relates to the collection of health information.

A key concept of privacy is that a person should be able as far as practicable to control the use and disclosure of their personal information. Health information may be particularly sensitive and consumers will need to be confident that information provided to health practitioners in a Primary Care Partnership (Partnership) will be handled appropriately and confidentially and any disclosures managed in accordance with the consumers' wishes (unless otherwise required by law).

Partnerships should foster open information handling policies and encourage member agencies to communicate those policies and practices at the time of collection so that people are aware of:

- What personal and health information is being collected
- Why it is being collected
- How it will be used and
- To whom it may be disclosed.

WHAT INFORMATION CAN BE COLLECTED?

Partnership member agencies should only collect information that is **necessary** to undertake core services or related functions (eg billing for services) and only where some specified requirements are met, including in particular:

- The consumer **consents** (willingly provided information is usually sufficient to imply consent to collection of information) and / or
- The collection is required, authorised or permitted by **law or law enforcement** purposes and / or
- The information is received through an appropriate **disclosure** by another organisation such as a health service (ie, with consumer's consent, agency x refers consumer to agency y) and / or
- The collection is necessary to prevent or lessen a **serious threat** to life, health or safety of an individual or the public

The onus is placed on the collecting agency to justify the data that is being collected. In the case of health information, practitioners should continue to use their professional judgement in deciding what information is necessary for the delivery of suitable health care. To assist in this process a set of **Initial Needs Identification** tool templates has been developed to enable capture of core demographic and health information that, used collectively can assist in undertaking health care assessments and inform the ongoing care planning.

HOW SHOULD INFORMATION BE COLLECTED?

In collecting information, health practitioners should be sensitive to the consumer's circumstances, in particular:

- Cultural requirements of certain individuals or communities eg need to provide access to female practitioners where appropriate
- Special communication needs of individuals such as the aged and those with sensory disabilities
- Allowing consumers to retain anonymity where practical, safe and lawful.

Partnership member agencies should also consider the appropriateness of the physical environment in which information is collected and provide private interviewing facilities where practicable.

Partnerships should reflect agreed practices and processes for information collection in an agreed protocol between member agencies.

INFORMATION SHEET 4 – COLLECTION OF INFORMATION

Quick Reference

Section 85(6) defines those categories of persons that may act as authorised representatives

*Information Sheet 6 **Capacity and Consent** provides further guidance on authorised representation*

'What Happens to Information About Me' contained within INI tool template provides a minimum standard for information that should be included in a consumer brochure

FROM WHOM SHOULD INFORMATION BE COLLECTED?

In most circumstances, information should only be collected from the individual concerned. In some cases, consumers may be **physically** unable to provide information because of a disabling illness or major injury or trauma.

In other cases, consumers may be **legally** unable to provide information (for example, young children, people with a severe illness or major injury, or people with a mental illness or other disability that impairs their legal decision making capacity).

Where a health practitioner is satisfied that the consumer does **not** have the physical or legal capacity to provide personal information then information may be sought from the individual's '**authorised representative**'. People who can act as authorised representatives are specified by law.

WHAT MUST CONSUMERS BE TOLD WHEN THEIR INFORMATION IS BEING COLLECTED?

Consumers must be made aware of how their information will be used, who will have access to it and their own rights of access and correction. Partnerships and member agencies should consider adopting as a minimum standard the **consumer information brochure**, *What Happens to Information About Me – A Guide for Consumers* that outlines the key points relating to management of health information and has been developed for use within the Initial Needs Identification tool template. (Copy attached).

SOME TIPS FOR COLLECTION OF HEALTH INFORMATION

- Develop a protocol that specifies the Partnership's acceptable practices and protocols around information collection
- Do not use undue pressure or coerce consumers to provide information
- Ensure that consumers are aware of the implications of providing or not providing information – for example, the benefits of their providing full and frank information to assist with a health assessment
- Advise consumers of their rights to access and to correct information held on their health records
- Provide information brochures and consent forms in a user friendly format and in a variety of community languages and provide access to interpreters if necessary
- Develop a comprehensive brochure advising consumers of their privacy rights and outlining the information handling practices of the organisation
- Place privacy posters and information brochures in public areas and bring this information to consumers' attention when collecting health and personal data
- Where it is intended to disclose information collected, consider adopting as a standard the consent form contained within the Initial Needs Identification tool template
- Where practicable, provide scripted procedures for front line reception staff to use in the collection of information

LEGAL ADVICE: DISCLAIMER

Information contained within this information sheet is not intended to substitute for legal advice. Primary Care Partnerships and / or member agencies should take advice from their legal advisors in determining whether their policies and practices comply with all relevant legislation.

INFORMATION SHEET 4 – COLLECTION OF INFORMATION

What happens to information about me? A guide for consumers

This service is one of a number of health care services that often work together to meet the health needs of residents in this area. This brochure provides some general advice on how your health information will be handled while you are a consumer of this service.

What happens to information about me?

When you become a consumer of this service a health record is created. It includes your name, address, contact details and information about your health. Every time you attend or have contact with us, new information is added to your record. This allows all health professionals involved with your care to access your information easily and quickly when it is needed.

Your health information is stored securely at this service. We will keep your health record for a minimum of 7 years after your last visit. The record will then be disposed of securely, as required by law.

Why is this information necessary?

We need to collect and keep this information to provide you with suitable health care. Your health record can help us to quickly identify which course of actions are likely to be safe and effective for you. It will also lessen the need to collect the same information over and over.

Some information may also be used for research and planning, to help us provide better health outcomes for the whole community. In this case, any **identifying** information, such as your name and contact details, will be removed before the information is used.

What rights do I have to access my health information?

You can ask to see any information held on your health record. This may include viewing the information, getting a summary or in some cases a fuller copy of your record, or having information explained to you if you wish. Some limits may apply where particular circumstances prevent us from releasing information. If any limits apply to your record, this will be explained to you.

You also have the right to correct any information in your record that you believe is incorrect, incomplete, out of date or misleading. You cannot ask that information held on your health record be removed, though you may ask that a correcting statement be added to it. For information on how you may request access and/or correction, please speak to one of our staff.

How will my information remain confidential?

We have strict policies about who can see and use your personal health information. All our staff members must treat your information confidentially. Your privacy is also protected by law. Generally, we only share personal or health information about you with people who are directly involved in your ongoing care, for the purpose of a particular care service. If we need to share your information for any other purpose we will ask for your agreement before doing so (unless otherwise required by law).

INFORMATION SHEET 4 – COLLECTION OF INFORMATION

What if I am unable to give consent?

In some cases, consumers may not be able to give consent because they are legally unable to make a decision about release of their information (for example, young people (children), people with a severe illness or major injury, or those with a mental illness or other impairment). In such cases, a decision will be sought from the consumer's authorised representative. People who can act as authorised representatives in these circumstances are specified by law. Your health care provider can give you more detail about this.

Who may have access to information about me?

We may recommend that other health care providers outside this service become involved in your care. In that case, you will be asked to give consent for us to disclose any necessary information from your health record to the other health care services, to help them assess your needs and provide you with relevant care.

Sharing information in this way helps us to provide you with effective services, and lessens the need for you to repeat your personal or health information to each new provider. Please note that you do have the right to refuse consent if you wish. If you have any concerns or questions about sharing of information, please speak to one of our staff.

When can information be disclosed to other people without my consent?

There are very few situations when your information may be shared without your consent. For example, in an emergency situation, we would have to release medical information about you to aid emergency treatment.

Also, in certain circumstances, this service may be required by law to release personal information about you. Examples include:

- Reporting of notifiable diseases to the Department of Human Services; or
- Providing health records to a court when required in relation to legal proceedings;
- Providing health records to a law enforcement agency (e.g. police) in response to a search warrant.

If any of these circumstances apply, we will advise you as close as we can to the time when the information is released.

What do I do if I have any complaints?

If at any time, you have a question about the way your personal health information is being managed, or you have a complaint in relation to privacy or confidentiality of your information, please contact us. If you are not satisfied with the way in which we handle your information or deal with your concerns you may make a formal complaint to the Health Services Commissioner on 8601 5225.

Who do I contact for more information?

Agency contact details: