Office of the Information Commissioner
Queensland

IPOLA

IPOLA GUIDELINE

Interpreting the legislation – Information Privacy Act 2009

QPP 3 & 6 – Health agencies: collection, use or disclosure of health information

This guide does not reflect the current law.

It highlights important changes to the *Information Privacy Act 2009*.

This guide does not constitute legal advice and is general in nature only. Additional factors may be relevant in specific circumstances. For detailed guidance, legal advice should be sought.

1.0 Overview

Queensland government agencies[1] must handle personal information in accordance with the Queensland Privacy Principles (**QPP**) in the *Information Privacy Act 2009* (Qld) (IP Act).

This guideline is based on and includes material from the Australian Privacy Principle guidelines developed by the Office of the Australian Information Commissioner.

1.1 What is a health agency?

A health agency is the Department of Health or a Hospital and Health Service (**HHS**).

1.2 What is personal information?

Section 12 of the IP Act provides that personal information means information or an opinion about an identified individual or an individual who is reasonably identifiable from the information or opinion, whether the information is true or recorded in a material form.

The individual does not need to be directly identified in the information for it to be personal information. It is sufficient if they can reasonably be identified by reference to other information.

[1] References to an agency in this guideline include a Minister, bound contracted service provider, or other entity required to comply with the QPPs.

Refer to ***Key privacy concepts – personal and sensitive information*** for more information.

1.3 What is health information?

'Health information' is a category of 'sensitive information'[2] and is personal information about an individual that includes any of the following:

- the individual's health at any time
- a disability of the individual at any time
- the individual's expressed wishes about the future provision of health services to the individual
- a health service that has been provided, or that is to be provided, to the individual
- personal information about the individual collected for the purpose of providing, or in providing, a health service; or
- personal information about the individual collected in connection with the donation, or intended donation, by the individual of any of the individual's body parts, organs, or body substances.

QPP 3 and QPP 6 contain specific provisions allowing the collection, use and disclosure of health information by a health agency where a 'permitted health situation' exists.

2.0 Permitted health situations

A health agency can, under QPP 3.4(c) and QPP 6.2(d), collect, use, or disclose health information for a 'permitted health situation'.

The permitted health situations are set out in schedule 4, part 2 of the IP Act:

- collection for provision of a health service
- collection, use or disclosure for certain research or statistical purposes, or collection for health service monitoring and management purposes; and
- disclosure to a responsible person for an individual.

2.1 Collection – provision of a health service

This permitted health situation allows health agencies to collect health information where it is necessary to provide a health service to an individual.[3]

2.2 Collecting, using or disclosing personal information for research

These permitted health situations allow for the collection, use, or disclosure of health information by a health agency where necessary for research, or the compilation or analysis of statistics, relevant to public health or public safety.[4]

[2] As defined in schedule 5 of the IP Act.
[3] Schedule 4, part 2, permitted health situation 2.
[4] Schedule 4, part 2, permitted health situation 3 (collection) and 4 (use or disclosure).

Health agencies may also collect health information for management, funding and monitoring purposes.[5]

2.3 Disclosure to a responsible person for an individual

This permitted health situation covers situations where a person is themselves incapable of giving or communicating consent to the disclosure by a health agency of health information necessary to allow for the individual's appropriate care or treatment, or for compassionate reasons. In these circumstances, health agencies may disclose health information to a person responsible for the individual (a 'responsible person'), where certain requirements are met.[6]

Each of these permitted health situations are discussed further below.

3.0 Collection in the provision of a health service

A health agency may collect health information about an individual if the information is necessary to provide a health service to the individual and either:

- the information collection is required or authorised by or under an Australian law, or
- the individual would reasonably expect the health agency to collect the information for that purpose.

A health agency can also collect health information that is a family or social medical history or other relevant information about an individual, if:

- it is necessary to collect the personal information for the purpose of providing the individual or another individual with a health service; and
- it is collected from the individual receiving or about to receive a health service or a responsible person for that individual.

See 5.2 for who constitutes a *responsible person* for the individual.

4.0 Collection, use or disclosure of health information for research and other purposes

A health agency may collect, use, or disclose health information without the consent of the individual if the collection, use or disclosure is necessary for research, or the compilation or analysis of statistics, relevant to public health or public safety. A health agency can may collect health information if it is necessary for the management, funding or monitoring of a health service.

These permitted health situations can only be relied on where:

- for ***collection*** – the purpose cannot be served by collecting information which does not allow the identification of the individual.

[5] Schedule 4, part 2, permitted health situation 3(1)(a)(iii).
[6] Schedule 4, part 2, permitted health situation 5.

- for ***collection*** – collection is authorised or required by or under an Australian law,[7] undertaken by a designated person with the approval of the relevant chief executive, or done in accordance with guidelines approved by the chief executive of the health department.

- for ***use or disclosure*** – the research must be conducted in accordance with guidelines approved by the chief executive of the health department.

- for ***disclosure***—the health agency reasonably believes that the entity receiving the health information will not disclose the health information or personal information derived from the health information.

In ***all*** cases, it must ***also*** be impracticable for the health agency to seek the individual's consent to the collection, use or disclosure.

Before a health agency can rely on the research permitted general health situations, it must first consider:

- is the collection, use or disclosure of health information necessary for the research? Can the same goal be achieved with unidentified or deidentified information?
- How effective will deidentification of the data in the final product of the research be? More than just a name can identify an individual, and reidentification may be possible.
- For a disclosure, what steps will the agency take to ensure the recipient does not disclose the personal information? The agency must be satisfied that the recipient will not disclose the information to anyone else.
- For a disclosure, is the information being communicated outside Australia? If so, the disclosure must comply with section 33 of the IP Act.
- Is it impracticable to seek the consent of the potential subjects?
- Is the work relevant to public health or public safety?

Deidentified or unidentified data

The privacy principles only apply to information that can be linked to an identifiable individual. If the information can be deidentified or broken down into aggregated unidentified data such as statistics, the use or disclosure can proceed without having to consider the QPPs.

Refer to ***Privacy and Deidentification*** (guideline under development) for assistance on deidentifying information.

[7] 'Australian law' is defined in schedule 5 of the IP Act as a 'law of the Commonwealth or a State, and includes the common law.'

4.1 Conducted according to health department guidelines

To rely on the research permitted health situations, the agency must ensure that research will be conducted according to guidelines issued by the chief executive of the health department – or, in the case of collection, under an Australian law requiring or authorising the collection, or by a 'designated person' with approval of the 'relevant chief executive'.[8]

4.2 Necessary

When considering whether the collection, use or disclosure of health information is necessary, the health agency must consider to what extent the personal information is needed for the research. It will be a question of degree, to be determined having regard to the purpose of the research, its intended outcomes, and the extent to which it is dependent on the personal or health information. If deidentified information would serve the same purpose, then the collection, use or disclosure of health information is not necessary.

4.3 Research

Research generally involves ethical investigation using a set methodology intended to achieve a specific result. It must begin with a clearly defined goal around which the study is designed. The data gathered as part of the research must be aimed at assisting the researcher towards achieving that goal.

It should be more than a reorganisation or restatement of the facts contained in the data; it must use a clear procedure to analyse a body of information or data and extract new meaning from it or develop unique solutions to problems or cases.

4.4 Statistics

Compilation or analysis of statistics is the act or process of collecting numerical data or undertaking a detailed examination of the elements or structure of numerical data, especially in or about large quantities, and inferring conclusions about the whole from conclusions reached from the whole or a representative sample.

4.5 Relevant to public health or public safety

For research to be relevant to public health or public safety there must be a sufficient link between the goal of the research and its possible impact on public health or safety. The results it is aimed at achieving, the questions it is attempting to answer, or the knowledge it is seeking to gain must be of potential benefit to the public generally, not just the agency which holds the information or the individual conducting the research.

Research relevant to public health or safety would commonly involve something beneficial to the well-being of society as a whole, or a specific segment of it.

[8] 'Designated person' and 'relevant chief executive' are defined in Schedule 4, part 2, permitted health situation 3(2) of the IP Act.

Research that may be in the public interest could include research into:

- public health issues
- public safety issues
- social welfare issues
- protection of children and disabled or disadvantaged members of society
- environmental health, protection, and improvement
- better delivery and increased effectiveness of government services.

All proposed research projects where personal information is considered necessary must be individually assessed to determine if they are actually relevant to public health or safety.

When making this assessment, agencies should consider:

- How is the public being defined? Does it go beyond the agency's own needs/potential benefit to consider the greater implications for the public as a whole?
- How is the public health or safety expected to benefit from, or be impacted by, this research? For example, will it bring greater knowledge, insight, or understanding or enhance the delivery or improve the effectiveness of a government health service?
- Is there a risk or a potential cost to the community if the research is not conducted?
- Are the potential subjects of the research at any risk of harm as a result of their personal information being used in this way?
- Is the research being conducted in an ethical way, consistent with the accepted standards for research involving human beings?

4.6 Impracticable to obtain consent

Consent is the best way of using or disclosing personal or health information for a secondary purpose.

A health agency can only rely on permitted health situations if it is impracticable to obtain the individual's consent. 'Impracticable' does not mean difficult or undesirable. To be impracticable, it must be impossible, or extremely difficult, to seek that agreement. The fact that seeking agreement is inconvenient or would involve expenditure of some effort or resources is not sufficient.

The impracticability of obtaining agreement must not be confused with the undesirability of obtaining agreement. For example, it is not sufficient that, if agreement were sought, refusal by some individuals would make the research project more difficult.

Whether it is impracticable to seek agreement will depend on the individual circumstances. When making this determination, the following are relevant considerations:

- the age of the information
- the size of the subject pool

- whether the individuals concerned are likely to have moved or died
- the lack of current or ongoing contact with the individuals, and a lack of sufficient information to determine their current contact details (bearing in mind the obligation to ensure information is accurate up to date, complete and relevant before use); and
- the resources required to obtain agreement would be a significant drain on the agency or researcher to the extent that the research could not be done.

4.7 Reasonably believe the receiving entity will not disclose

Where the health agency is disclosing, rather than using, the health information, the agency must reasonably believe that the entity receiving it will not disclose the health information to anyone else. The words 'reasonably believe' require that there be a reasonable basis for the belief, and not merely a genuine or subjective belief.

In addition, health agencies should ensure the entity will:

- appropriately safeguard the information against misuse, interference, or unauthorised access, modification or disclosure;
- not use the information for any other purpose; and
- return the information, or destroy it, at the conclusion of the research.

This could be achieved by way of a contract, Memorandum of Understanding, Deed of Privacy, or other instrument that binds the recipient of the information to deal with it in a specific way.

5.0 Disclosing health information to a responsible person for an individual

A health agency may disclose health information where:

- the health agency is providing a health service to the individual
- the recipient of the information is a responsible person for the individual
- that individual is physically or legally incapable of giving or communicating consent to the disclosure, or physically cannot communicate consent to disclosure
- a health professional providing health services for the health agency is satisfied that the disclosure is necessary for to provide appropriate care or treatment for the individual, or for compassionate reasons; and
- the disclosure is not contrary to any wish expressed by the individual before they became unable to give or communicate consent and the health professional is aware, or could reasonably be expected to be aware, of that wish.

Disclosure under this permitted health situation must be limited to that necessary to allow for appropriate care or treatment, or compassionate reasons.

What is a health professional?

Schedule 5 of the IP Act provides that a health professional is a person who is a health professional under schedule 2 of the *Hospital and Health Boards Act 2011*.

Disclosure necessary for an individual's care or treatment could include an occupational therapist telling a sibling, who provides care in the home, about aspects of an individual's current physical condition, to explain how to carry out certain personal care tasks.

Disclosure for compassionate reasons could include a doctor telling an individual's partner about an individual's injuries and prognosis following a car accident.

5.1 Disclosure contrary to the individual's wishes

In determining whether to disclose information to a person responsible, a health professional must consider whether this would be contrary to any known wishes of the individual.

5.2 A responsible person for the individual

As set out in schedule 5 of the IP Act, a 'responsible person' for an individual is a:

- parent of the individual; or
- a child or sibling of the individual who a health professional believes has capacity; or
- a spouse of the individual; or
- a relative of the individual if the relative is a member of the individual's household; or
- a guardian of the individual; or
- a person exercising a power under an enduring power of attorney made by the individual that is exercisable in relation to decisions about the individual's health; or
- a person who has sufficient personal interest in the health and welfare of the individual; or
- a person nominated by the individual to be contacted in case of emergency.

Whether someone is a 'responsible person' will depend on the nature of the relationship between the person and the individual. Depending on the circumstances, a person with sufficient personal interest in the health and welfare of the individual' could include a romantic partner, someone in a close relationship or friendship with the individual, a housemate, or a companion or carer of the individual.

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For additional IPOLA assistance, please contact the IPOLA team by email IPOLA.Project@oic.qld.gov.au

For information and assistance on current legislation, please refer to the OIC's guidelines, or contact the Enquiries Service on 07 3234 7373 or by email enquiries@oic.qld.gov.au

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