Guideline – Disclosure of Confidential Information for Research

Queensland Health (**Department**) has prepared this document for general guidance purposes for its staff. Hospital and Health Services (**HHSs**) may refer to the guidance in this document, however this is not obligatory, and HHSs may provide separate guidance material for their staff.

This Guideline is not intended to and does not constitute legal advice. Departmental employees may request advice from the Legal Branch, and HHS staff may request advice from an HHS legal service, before applying the information in this Guideline to particular circumstances.

List of Acronyms	
GAA	*Guardianship and Administration Act 2000* (Qld)
HHBA	*Hospital and Health Boards Act 2011* (Qld)
HREC	Human Research Ethics Committee
IPA	*Information Privacy Act 2009* (Qld)
NHMRC	National Health and Medical Research Council
NPPs	National Privacy Principles
PCCO	Privacy and Confidentiality Contact Officer
PHA	*Public Health Act 2005* (Qld)
QCAT	Queensland Civil and Administrative Tribunal
RTIA	*Right to Information Act 2009* (Qld)

1. Introduction

Information held by the Department and HHSs, including clinical records and public health data, plays an important role in clinical research and generating an evidence base to improve healthcare services and health outcomes for individuals. Clinical and public health information is collected and held by the Department and HHSs under different legislative regimes.[1] Generally speaking, the information will be strictly protected as confidential and a legal authority is required to use the information for research purposes, whether by QH employees or a third party. For ease of reference, the Guideline will refer to the information concerned collectively and interchangeably as **Identifying Data**.

This Guideline has been developed to explain at high level the legislative frameworks applicable when seeking disclosure of Identifying Data for research purposes. Researchers are encouraged to seek advice about individual matters where appropriate. Even where a lawful basis is identified for the disclosure of confidential information, there are situations where a decision maker within the Department or an HHS may exercise a discretion not to disclose it.

2. Overview

Identifying Data that could identify an individual patient or client is protected by legislation in Queensland. A lawful authority must be identified prior to disclosure by the Department or an HHS.

The primary options relevant to research will be disclosure:

- with consent of the individual, parent, or guardian (**4.2.1**) or substitute decision-maker or QCAT (**4.2.2**); or
- under Part 7 of the *Hospital and Health Boards Act 2011* (Qld) (**HHBA**) (e.g. section 150) (**4.3.2**); or
- with approval under Chapter 6, Part 4 of the *Public Health Act 2005* (Qld) (**PHA**) (**4.3.3**).

[1] For example when providing public sector health services, maintaining public health registers and performing other functions. The public health registers include Notifiable Conditions Register, Queensland Cancer Register, Notifiable Dust Lung Disease Register and Pap Smear Register.

The answers to the following threshold questions will help to resolve which disclosure pathway will be most appropriate for the activity.

Preliminary question	Why it is important	Guideline Reference
1. What type of information is being sought?	To assess whether the information sought is protected by legislation, and if so, which Acts and provisions are relevant to the information sought.	**3.1 & 4.1**
2. Has consent been obtained?	Best-practice and preferred method of data disclosure is with the informed consent of the person to whom the information relates.	**4.2.1**
3. What is the requestor's role or position?	Certain HHBA disclosure provisions only apply if the recipient is a 'designated person' as defined in section 139A of that Act (e.g. section 150(a)).	**4.3.2**
4. What is the purpose of disclosure?	To assess which disclosure pathway is appropriate. Some legislative provisions only allow disclosure for specific purposes.	**4.2**

3. Legislative Confidentiality and Privacy Protections

3.1 What confidentiality and privacy protections apply to Identifying Data?

Strict confidentiality and privacy protections apply to Identifying Data under various legislative regimes in Queensland including the HHBA, IPA, PHA and *Guardianship and Administration Act 2000* (Qld) (**GAA**).

Each of these Acts varies in relation to the scope of information that is protected by privacy and confidentiality restrictions. In most cases, Identifying Data will be both 'confidential information' protected under the HHBA and 'personal information' or 'health information' regulated under the IPA. These terms are defined in the relevant legislation as follows:

Confidential Information under the HHBA (section 139) means:

a) information, acquired by a person in the person's capacity as a designated person, from which a person who is receiving or has received a public sector health service could be identified; or

b) information accessed by a prescribed health practitioner under s 161C(2).

Personal Information under the IPA (section 12) is information or an opinion, including information or an opinion forming part of a database, whether true or not and whether recorded in material form or not, about an individual whose identity is apparent or can be reasonably ascertained, from the information or opinion.

Health Information under the IPA (Schedule 5) is *'personal Information'* about an individual that includes, among other things, information about their health or disability at any time, their expressed wishes about the future provision of health services to the individual, and a health service that has been provided, or is to be provided to them.[2]

The confidentiality requirements in the HHBA apply even if the person who could be identified from the disclosure of confidential information is deceased.[3] The IPA does not apply to deceased persons.[4]

Under section 142 of the HHBA, designated persons must not disclose, directly or indirectly, 'confidential information' (as defined in s 139 – see above) to another person unless the disclosure is required or permitted under the HHBA. A *designated person* under the HHBA includes, among others, employees of the Department and an HHS, and health professionals who are engaged to deliver public sector health services (see full definition in section 139A of the HHBA).

See section **5** of this Guideline for further information regarding the requirements of the IPA, and the interrelationship between the HHBA, IPA and PHA in the context of disclosure and use of Identifying Data.

[2] *Information Privacy Act 2009* sch 5.
[3] *Hospital and Health Boards Act 2011* s 142(3).
[4] The *Information Privacy Act 2009* applies to individuals defined in the *Acts Interpretations Act 1954* as natural persons.

It should also be noted that for some types of information, specific legislative regimes are in place that set out the confidentiality and disclosure requirements applicable to that information. For example:

- Information in **registers maintained under the PHA** (e.g. notifiable conditions register) - approval under Chapter 6, Part 4 (Research) of the PHA should be sought if this information is required for research purposes.
- Information from the **My Health Record** (which may be accessible in the Viewer for patient care). This information must be used in accordance with the requirements of the *My Health Records Act 2012* (Cth) and the Australian Government Framework to guide the secondary use of My Record System data[5].

3.2 Access to Queensland Health Information Systems

Even if an employee has direct access to patient information (e.g. the ieMR) for clinical purposes, they will need to identify a legal authority if seeking to access and use that information for research purposes.

Access to Queensland Health information systems[6] containing confidential information may be given to external persons in the limited circumstances permitted in the legislation[7] (e.g. for prescribed health professionals). Legal advice is recommended if the method of disclosure for research is proposed to be by 'access' to a Queensland Health information system.

For information regarding obtaining access to applications in Queensland Health, see Access to Queensland Health (QH) Application - Internal and Access to Queensland Health (QH) Application Containing Patient Data – External.

3.3 What are the consequences for breach of the confidentiality obligations under the HHBA?

A failure to comply with the duty to keep Identifying Data confidential is a criminal offence under the HHBA which carries a maximum penalty of 100 penalty units.[8] A breach of confidentiality may also form grounds for a disciplinary process under the *Code of Conduct for the Queensland Public Service* and contravene other Acts and laws (including the *Human Rights Act 2019* (Qld) and common law) that protect confidential information and privacy.

See also Queensland Health Digital Standard Information access, use and disclosure (QH Intranet).

4. Disclosure of Information

4.1 Disclosure of information that could not identify an individual

The confidentiality requirements in the HHBA apply to information '**from which a person who is receiving or has received a public health service could be identified**'.[9] The IPA protects *personal information* and *health information* '**about an individual whose identity is apparent or can reasonably be ascertained, from the information or opinion**'.[10] Therefore, it is important to assess whether an individual could be identified from the information sought to be disclosed. This assessment must take account of not only direct identifiers such as name and address, but also any other information that can potentially identify an individual when combined, such as postcode, principal diagnosis, procedures, co-morbidities, encounter dates and age.

If the information could not identify an individual, it may be disclosed by the Department or an HHS without contravening applicable legislation because it does not fall within the definitions of '*confidential*' or '*personal*' or '*health*' *information*.

De-identification and anonymisation are processes which support the sharing or dissemination of data ethically and legally, thereby realising its social, environmental and economic value, whilst preserving confidentiality. De-identification and anonymisation are used by government agencies for the protection of confidential and sensitive information, to build trust and meet community expectations around the handling of data.[11]

[5] Framework to guide the secondary use of My Health Record system data | Australian Government Department of Health and Aged Care
[6] Information system means a system for making, keeping and preserving records, whether paper based, electronic or both, including records that contain confidential information (s. 139 HHBA).
[7] For example, see sections 161A – 161C of the *Hospital and Health Boards Act 2011*
[8] *Hospital and Health Boards Act 2011* s 142(1).
[9] See full definition of confidential Information s 139 HBBA.
[10] See full definition of personal information and health information in s 12 and Schedule 5 of the IPA, respectively.
[11] eHealth Queensland De-identification and Anonymisation of Data Guideline (QH Intranet); De-identification and the Privacy Act (2018) | Office of the Australian Information Commissioner

For some research projects, it may be possible to anonymise or de-identify the relevant information prior to disclosure, by removing or altering information that could identify an individual. This may enable the agency to disclose the information while still complying with the legislation.[12]

Anonymisation involves the permanent removal of identifying information, with no identifying information kept separately. De-identification is the removal of identifying information from a dataset, and this data could potentially be re-identified, for example, when the data is linked with other information or data sets.[13] When the Department or an HHS discloses de-identified data, they must adequately manage re-identification risk to protect the identity of individuals. [14] De-identification and anonymisation can be complex and often require specialist advice.

Legal advice, or advice from the Privacy and Confidentiality Contact Officer (**PCCO**)[15] for the Department or an HHS (as applicable) may be required when considering whether information can be disclosed on the basis that it could not identify an individual and is not-re-identifiable.

4.2 Disclosure pathways for information that could identify an individual

If the Identifying Data is in an identifiable or re-identifiable format, as will usually be the case for clinical records or a public health register, a lawful basis for disclosure will need to be established. The major pathways to disclosure for research purposes are as follows:

- disclosure by the Department or an HHS with consent (see sections **4.2.1** and **4.2.2** below); or
- lawful disclosure by a '*designated person*' under the HHBA in specific and limited circumstances[16] (see sections **4.3.2** below); or
- application and approval from the Chief Executive or delegate in the Department under the PHA[17] (see section **4.3.3** below).

4.2.1 Disclosure with consent of the individual or parent/guardian

The best-practice and preferred method for seeking disclosure of Identifying Data is with the informed consent of the person to whom the information relates.

Adults and children with sufficient age and maturity (known as 'Gillick competency') may consent to their '*confidential*', '*personal*' or '*health*' information being disclosed for use in research.[18] The HHBA specifies that if the confidential information relates to a child, the disclosure must be by a health professional and:

- The child may consent to the disclosure if the health professional reasonably believes the child is of sufficient age and mental and emotional maturity to understand the nature of consenting to the disclosure.[19]
- The parent or guardian may consent to the disclosure if the health professional reasonably believes the child is of **insufficient** age or mental or emotional maturity.[20]

The consent for use of a potential participant's confidential information or personal information in research must be voluntary and based on clear information about the specific purpose for which the disclosure is sought, and how the information will be used, stored and protected.[21] [22] **Consent should be obtained in accordance with the *Department Research Management Standard*[23] and the *National Statement on Ethical Conduct in Human Research 2007*[24].**

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[12] See eHealth Queensland publications De-identification and Anonymisation of Data Guideline; Definitions for Identifiable, De-identified, Non-identifiable, Re-identified and Anonymised Data; and Data Classification Tool (QHEPS intranet);
[13] eHealth Queensland Definitions for Identifiable, De-identified, Non-identifiable, Re-identified and Anonymised Data (QHEPS Intranet);
[14] For general information regarding de-identification techniques, and assessing and managing re-identification risks, refer to Privacy and de-identified data | Office of the Information Commissioner Queensland (oic.qld.gov.au) and A framework for data de-identification - Data61 (csiro.au). Note that these guides are based on the relevant privacy legislation, and do not specifically address the scope of confidential information defined under the HHBA.
[15] PCCO contact list at: https://www.health.qld.gov.au/system-governance/contact-us/access-info/privacy-contacts.
[16] *Hospital and Health Boards Act 2011* pt 7.
[17] *Public Health Act 2005* chap 6 pt 4.
[18] *Hospital and Health Boards Act 2011* s 144(a)–(b); *Information Privacy Act 2009* sch 4 National Privacy Principle 2(1)(b).
[19] *Hospital and Health Boards Act 2011* s 144(b)
[20] *Hospital and Health Boards Act 2011* s 144(c).
[21] National Statement on Ethical Conduct in Human Research (2007) - Updated 2018 / | NHMRC Chapter 2.2.
[22] For guidance in relation to obtaining consent from research participants who are Aboriginal or Torres Strait Islander people see Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders (2008) / | NHMRC.
[23] Research Management Standard (health.qld.gov.au), QH-IMP-013-1:2015, Section 3.9; National Statement on Ethical Conduct in Human Research (2007) - Updated 2018 / | NHMRC Chapter 2.3; Queensland Health, Confidentiality General Principles – Hospital and Health Boards Act 2011 p.9.
[24] National Statement on Ethical Conduct in Human Research (2007) - Updated 2018 / | NHMRC

Note: While consent will provide a lawful basis for disclosure by a designated person under the HHBA, a Human Research Ethics Committee (**HREC**) process will also be required when information is disclosed for research purposes.[25] HREC approval constitutes ethical approval only and by itself does not constitute a lawful basis for disclosure of Identifying Data or for research to commence.

Contacting patients/clients to obtain consent for disclosure of confidential information

Under section 161 of the HHBA, a designated person may disclose confidential if the disclosure is necessary or incidental to another permitted disclosure under that part of the Act (such as disclosure with consent under section 144.)

Therefore, a designated person or prescribed health practitioner may access contact details for a person to seek their consent to disclose their confidential information to a researcher.

4.2.2 Consent for disclosure of confidential information relating to an adult who lacks capacity

Section 150A of the HHBA allows for the disclosure of confidential information for approved research regarding adults with impaired capacity.[26] If the Director-General of the Department, or a Chief Executive of an HHS gives written approval for the research, and there is consent by a substitute decision-maker[27] or the QCAT,[28] a *designated person* may disclose the confidential information to the researcher.

Consent by substitute decision-maker:

If the Identifying Data relates to an adult who lacks capacity, the person's substitute decision-maker for a *health matter* may be able to provide consent to disclosure of confidential information for certain studies under the GAA.

> *Health matter* is defined as being a matter relating to *health care*, other than *special health care*[29] of the adult.[30]
>
> *Health care* of an adult, is defined as meaning, among other things, care or treatment of, or a service or a procedure for the adult – to diagnose, maintain, or treat the adult's physical or mental condition, and carried out by, or under the direction or supervision of, a health provider.[31]

Consent by Queensland Civil and Administrative Tribunal:

If the research relates to *special health care* or *experimental health care*,[32] it will be necessary to apply to the QCAT to approve disclosure of the person's confidential information for approved research.[33]

For further information see Clinical Research | Queensland Civil and Administrative Tribunal (qcat.qld.gov.au) and Special health care | Queensland Civil and Administrative Tribunal (qcat.qld.gov.au).

4.3 Disclosure without consent

4.3.1 Relevance of HREC waiver of requirement to obtain participant consent for research using personal information

In some circumstances it is not possible or practicable to obtain each individual's consent, and an HREC may waive the requirement for consent for medical research using Identifying Data.[34] This may be the case where the quantity, age or accessibility of clinical records or risk of bias will make obtaining consent very difficult or invalidate the results.

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[25] Research Management Policy, QH-POL-013:2015 and Research Management Standard (health.qld.gov.au), QH-IMP-013-1:2015. See also the Queensland Health *Research Ethics and Governance Health Service Directive,* which requires all research applications to comply with the National Health and Medical Research Council (**NHMRC**), *National Statement of Ethical Conduct in Human Research 2007* and the NHMRC, Australian Research Council and Universities Australia, *Australian Code for the Responsible Conduct of Research 2007*.
[26] *Hospital and Health Boards Act 2011* s 150A.
[27] A person authorised under a law to make decisions for an adult with impaired capacity (such as a statutory health attorney).
[28] *Hospital and Health Boards Act 2011* s 150A.
[29] *Guardianship and Administration Act 2000* sch 2 pt 2 s 7.
[30] *Guardianship and Administration Act 2000* sch 2 pt 2 s 4.
[31] *Guardianship and Administration Act 2000* sch 2 pt 2 s 5.
[32] *Guardianship and Administration Act 2000* sch 2 pt 2 s 12.
[33] *Guardianship and Administration Act 2000* s 72.
[34] National Statement on Ethical Conduct in Human Research (2007) - Updated 2018 / | NHMRC, Chapter 2.3.9 – 2.3.11.

In addition to obtaining an HREC waiver of consent, researchers need to ensure that the use or disclosure of Identifying Data without consent, is lawfully permitted under applicable legislation i.e., they need to identify a lawful disclosure pathway. HREC approval constitutes ethical approval only and is not a sufficient mechanism in itself.

4.3.2 Disclosure for evaluating, managing, monitoring, planning health services under section 150 of the HHBA

The HHBA allows for the disclosure of confidential information for purposes that are related to health services.[35] A *designated person* may disclose information to another *designated person,* or to an entity prescribed under a regulation,[36] where the purpose is for *evaluating, managing, monitoring or planning health services*.

A *health service* is defined broadly as being 'a service for maintaining, improving, restoring or managing people's health and wellbeing',[37] and includes:

- hospitals and other health facilities; and
- services dealing with public health such as a program or activity for the prevention and control or disease or sickness, the prevention of injury or protection and promotion of health.

  (see full definition in section 15 of the HHBA).

While section 150 of the HHBA does not specifically refer to *research*, the provision may apply in limited circumstances to some research undertaken **by a *designated person* in their capacity as a *designated person***, to permit disclosure between designated persons. There must be a sufficient relationship between the disclosure and evaluating, managing, monitoring or planning health services for the disclosure to be covered by the exception in section 150.

If a disclosure provision in the HHBA (such as 150(a)) requires the recipient (the person to whom the information is disclosed) to be a *designated person*, then the recipient **must** be acting in their capacity as a *designated person* in undertaking the research for which the disclosure is requested. For example, a person will be a *designated person* while carrying out their duties and functions as a Queensland Health employee, but the same person may not be acting as a *designated person* while carrying out duties for a second employer, or conducting research for the purpose of private study.[38]

The application of section 150 of the HHBA to any particular research purpose will depend on the circumstances or details of the disclosure so it is not possible to provide blanket guidance.

Factors to consider in deciding whether to apply section 150(a) of the HHBA to disclose Identifying Data (**disclosed information**) for a particular research purpose include:

a) disclosure must be from a *designated person* to a *designated person* who is acting in their capacity as a *designated person* when receiving and using the disclosed information; and

b) the recipient must be using the disclosed information as part of their ordinary duties as a *designated person* for the primary purpose of *evaluating*, *managing*, *monitoring* or *planning health services*; and

c) the subject matter of the research must relate directly to a *health service* as defined in section 15 of the HHBA (i.e. a system of delivering health care or a connection with existing or intended treatment of patients, rather than a theoretical development or development of a new treatment).

Section 150(a) of the HHBA does not provide legal authority for the designated person who is permitted to access the information to disclose the confidential information to third parties, such as research collaborators who are not designated persons. A separate legal authority would need to be identified for such further disclosure, such as participant consent (see section **4.2.1** above), or the data would need to be appropriately anonymised (see section **4.1** above).

[35] *Hospital and Health Boards Act 2011* s 150.
[36] For the list of currently prescribed entities, see *Hospital and Health Boards Regulation 2012* s 35.
[37] *Hospital and Health Boards Act 2011* s 15.
[38] Note that some students being educated in public health service will be designated persons in specific circumstances - see *Hospital and Health Boards Act 2011* s 139A(1)(h).

It should be noted that the PHA contains specific confidentiality regimes for the notifiable conditions register and other registers.[39] Section 150(a) of the HHBA should not be used to authorise disclosure of information in these registers. Approval under section Chapter 6, Part 4 of the PHA should be sought if this information is required for research purposes.

Legal advice, or advice from the PCCO[40] for the Department or an HHS (as applicable) may be required when considering whether section 150 of the HHBA applies to the proposed research activity purpose. Local HHS or departmental policies or procedures may apply in relation to approval to disclose confidential information under this provision.

For healthcare evaluation resources see Resources Library | Queensland Health Intranet.

Will research ethics and governance processes be required for projects using confidential information disclosed under section 150 of the HHBA?

As described above, section 150 of the HHBA is a permission to use confidential information for health services purposes. If this use includes a research element, then a research approval pathway is appropriate. For further information regarding research ethics and governance refer to Office of Research and Innovation.

4.3.3 Disclosure for research under Chapter 6, Part 4 of the PHA

An approval under Chapter 6, Part 4 of the PHA allows *health information held by a health agency* (Department or an HHS) to be disclosed for research purposes irrespective of consent from the individual to whom the information relates.

Health information held by a health agency:

a) means:

ii) information held by the agency about a person's health or the provision of a health service to a person; or

iii) information about a person's health or the provision of a health service to the person obtained by the agency under the PHA or other legislation; or

iiii) information about a person's health or the provision of a health service to a person held or obtained by an approved operator under chapter 6, part 3A for the purpose of keeping the Notifiable Dust Lung Disease Register; or

iiv) for chapter 6, part 4 [research], information about a person's health or the provision of a health service to a person, held or obtained by a contractor for the contractor to keep the Queensland Cancer Register; and

b) includes information about a person who is deceased.[41]

Research is defined for the purposes of these provisions in section 280 of the PHA.

An application for information under these provisions must be made in writing. The chief executive or delegate may grant the application only if satisfied of the matters specified in section 284(2) of the PHA.

Approval under these PHA provisions allows the information to be given by a *relevant person* (section 281). Section 281(4) defines a *relevant person* to be a 'person who has access to health information held by a health agency, including, for example, a health service employee or a public service employee'.

The term *relevant person* in s 281(4) is different from, and should not be confused with a *designated person* under section 139A of the HHBA.

Note that the PHA approval notice will state a description and purpose of the research for which the approval is provided. A person given health information under these provisions must not use the information for a purpose inconsistent with the research for which the information is provided.[42] The PHA also imposes restrictions regarding the further disclosure of health information received under these provisions.[43]

[39] Sections 77, 105, 175, 220, 228I, 238, and 248 PHA.
[40] PCCO contact list at: https://www.health.qld.gov.au/system-governance/contact-us/access-info/privacy-contacts.
[41] *Public Health Act 2005* sch 2.
[42] *Public Health Act 2005* s 290. Maximum penalty for contravention -50 penalty units.
[43] *Public Health Act 2005* s 291. Maximum penalty for contravention -50 penalty units.

Departmental procedures require authorisation from all relevant Queensland Health data custodians[44] prior to submission of applications for information under the PHA provisions.

Further information about making an application under the PHA for disclosure of confidential information is at: Use of Confidential Health Information.

5. Privacy and the IPA

As health agencies, the Department and HHSs must comply with the National Privacy Principles (**NPPs**) (section 31) and provisions relating to the transfer of information outside of Australia (IPA section 33) and contracted service providers (section 35) in the IPA.

NPP 2(1)(a) states that a health agency must not use or disclose *personal information*[45] about an individual for a purpose other than the primary purpose for which it was collected unless an exception applies. As such, the **scope of the consent** obtained or the PHA Chapter 6, Part 4 approval granted is important, particularly where information is **proposed to be used for future research**.

The IPA defines the terms 'use' and 'disclosure' in a particular way for the purposes of that Act. More information on those terms is available at the Office of the Information Commissioner: Key privacy concepts – use and Key privacy concepts – disclosure.

While the IPA contemplates '*personal information*' and '*health information*' being used or disclosed for research under certain conditions, it does not override the provisions of other Acts prohibiting the disclosure of Identifying Data, including the HHBA.[46]

Accordingly, the decision to disclose Identifying Data for research must be made in accordance with the HHBA or the PHA.

IPA provisions other than those relating to 'disclosure' will apply to Identifying Data in the same way they apply to other types of personal information. These include, for example, the way the information is collected, stored, secured, used, and disposed of etc. See eHealth Queensland Data Access Pre-planning Considerations Checklist [on QHEPS intranet] for further information regarding privacy considerations.

Version Control

Version	Date	Comments
1	May 2023	New document

[44] https://www.health.qld.gov.au/__data/assets/pdf_file/0034/843199/data_custodian_list.pdf
[45] See definition of personal information under the IPA in section **3.1** of this Guideline.
[46] *Information Privacy Act 2009* s 7(2).