



# Human Services Dataset Privacy Policy

Summary: Outlines how Personal and Health Information in the Human Services Dataset is managed. Outlines access to personal information and how to lodge a privacy complaint (internal review).



# Document approval

The Human Services Dataset Privacy Policy has been endorsed and approved by:

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(FACSIAR)

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# Table of contents

<b>1</b>	<b>Purpose of policy</b> .....	<b>4</b>
	1.1 Purpose .....	4
	1.2 Background and policy links.....	4
<b>2</b>	<b>Scope and application</b> .....	<b>4</b>
<b>3</b>	<b>Legislation</b> .....	<b>4</b>
<b>4</b>	<b>Privacy Policy statement</b> .....	<b>5</b>
	4.1 Authority to collect and disclose Personal and Health Information .....	5
	4.2 How Personal and Health Information is used in the Human Services Dataset .....	6
	4.3 Management of access to and disclosure of Personal and Health Information.....	6
	4.4 Security, retention and disposal of information.....	7
	4.5 Accessing and correcting Personal and Health Information .....	8
	4.6 Making a privacy complaint (Internal Review) .....	8
<b>5</b>	<b>Roles and responsibilities</b> .....	<b>9</b>
	5.1 Data Custodian .....	9
	5.2 The Stronger Communities Data Partnership (SCDP).....	9
	5.3 The Human Services Data Set Governance Advisory Committee (HSDGAC) .....	10
	5.4 The Project Team .....	10
	5.5 The Project Privacy Officer .....	10
	5.6 The Centre for Health Record Linkage.....	10
	5.7 The Australian Government Linkage Agency .....	11
	5.8 The Data Analytics Entity .....	11
	5.9 Approved Analysts .....	11
<b>6</b>	<b>Monitoring, evaluation and review</b> .....	<b>12</b>
<b>7</b>	<b>Support and advice</b> .....	<b>12</b>
<b>8</b>	<b>Definitions</b> .....	<b>12</b>
<b>9</b>	<b>Annexure 1: Internal Review Form</b> .....	<b>17</b>

# 1 Purpose of policy

## 1.1 Purpose

This policy is designed to outline:

- what Personal and Health Information is collected and shared as part of the Human Services Dataset (HSDS);
- how Personal and Health Information is collected, stored, used and disclosed;
- how you can apply to access or correct your Personal and Health Information;
- how to lodge a privacy complaint (Internal Review).

## 1.2 Background and policy links

This policy was developed in consultation with the Human Services Dataset Governance Advisory Committee (HSDGAC).

This policy is linked to the Privacy Stance.

# 2 Scope and application

This policy is to be followed by the FACS Insights Analysis and Research (FACSIAR) HSDS Governance and Privacy Project Team, Data Linkage Centres, Australian Government Linkage Agency, Data Analytics Entity and Approved Analysts.

This policy applies to Personal and Health Information collected from children, young people and their families and carers (Project Cohort) for the HSDS.

# 3 Legislation

This policy supports compliance with the following legislation and policies:

- [Public Interest Direction made under section 62\(1\) of the \*Health Records and Information Privacy Act 2002\* \(NSW\)](#)
- [Public Interest Direction made under section 41\(1\) of the \*Privacy and Personal Information Protection Act 1998\* \(NSW\)](#)
- [\*Privacy and Personal Information Protection Act 1998\* \(NSW\)](#)
- [\*Health Records and Information Privacy Act 2002\* \(NSW\)](#)
- [\*Data Sharing \(Government Sector\) Act 2015\* \(NSW\)](#)
- [\*State Records Act 1998\* \(NSW\)](#)
- [\*NSW Data and Information Custodianship Policy\*](#)
- [\*NSW Cyber Security Policy\*](#)

- [NSW Government Information Classification, Labelling and Handling Guidelines](#)
- [NSW Information Management Framework](#)
- [DCJ Privacy Management Plan](#)

## 4 Privacy Policy statement

### 4.1 Authority to collect and disclose Personal and Health Information

The collection of Personal and Health Information for the HSDS is enabled by the Public Interest Direction (PID) made under section 41(1) of the *Privacy and Personal Information Protection Act 1998* (NSW) and the Health PID made under section 62(1) of the *Health Records and Information Privacy Act 2002* (NSW) (PIDs).

Agencies participating in the HSDS have collectively signed a Memorandum of Understanding for the sharing human services information.

These agencies include:

- the Department of Communities and Justice (including the NSW Bureau of Crime Statistics and Research),
- NSW Registry of Births, Deaths and Marriages,
- Legal Aid NSW,
- NSW Police Force,
- NSW Department of Education,
- NSW Education Standards Authority,
- NSW Ministry of Health,
- NSW Ambulance,
- Revenue NSW.

Each agency involved in the HSDS collects information, including Personal and Health Information, related to its functions or activities. The data that is collected as part of the HSDS facilitate the Project Objectives which is to help ensure efforts and funding are focused on interventions that will improve long-term outcomes for vulnerable children, young people and their families, and, to design and deliver better services for this cohort.

Under the PIDs, agencies disclose information to a specialist NSW data linkage centre, the Centre for Health Record Linkage (CHeReL). For this disclosure to occur, agencies must have originally collected the information lawfully.

## 4.2 How Personal and Health Information is used in the Human Services Dataset

The Personal and Health Information that is disclosed by agencies to the Data Linkage Centre for the HSDS includes:

- identifying information, such as names and addresses;
- other personal characteristics of individuals, including sex, education level attained, postcode, place of birth, languages spoken at home and whether they are an Indigenous person or not;
- information about individuals' pathways of entry into, usage and interaction with, NSW and other Australian government services and systems, including the child protection, education and justice systems;
- characteristics of the Project Cohort requiring government protection, support or assistance (including children or young people who have come into contact with the Protection System);
- information about the family, socio-cultural and economic background of individuals and their families;
- health service provider or hospital records (including hospital admission and discharge records);
- information or an opinion about the physical or mental health or disability of an individual;
- information or an opinion about an individual's express wishes about the future provision of a Health Service to him or her; and
- healthcare identifiers.

Personal Information like names, addresses and government identifiers are removed as a part of the de-identification and linking process undertaken by the Data Linkage Centre, to ensure individuals cannot be identified and that privacy is protected.

De-identified and combined data is used for research and analysis to better understand, prioritise and evaluate the effectiveness of government policies, programs and services supporting vulnerable children, young people and their families.

## 4.3 Management of access to and disclosure of Personal and Health Information

Access to information, including Personal and Health Information, is managed in accordance with the PIDs and leading privacy practice.

To protect privacy of individuals, the HSDS can only be accessed by authorised personnel in secure environments for approved projects.

All entities and persons that are provided with access to Personal and Health Information are subject to privacy and confidentiality obligations to protect it from loss, unauthorised use and disclosure.

The Separation Principle is applied to handle Personal and Health Information during the de-identification and linking process. This means that access to Personal Information and other information (such as content data) is provided on a need to know basis and in accordance with staff roles. For example, at the data linkage centre the team handling Personal Information is functionally separate to the team handling other information. After identifiable Personal Information such as names and addresses are replaced with unique identifiers, another team combines the content data with the identifiers.

Analysis of de-identified information can only be conducted by approved researchers and analysts ('Approved Analysts') from government agencies, research institutions or contracted service providers for approved projects. Data users are legally obliged to use the information only for Approved Purposes, adopt best privacy, security and de-identification practices, and keep the information confidential, secure and protected from loss, unauthorised use or disclosure. Approved Analysts must complete privacy training before accessing the data. Only de-identified and aggregated data can be released from the secure analytic environment after checks have been completed.

Personal Information can be disclosed to the Commonwealth for linkage with Commonwealth data. Similar access and security controls are applied as to its use and storage.

#### 4.4 Security, retention and disposal of information

The privacy, security and integrity of information collected for the HSDS is maintained through robust legislative safeguards and leading data and privacy practice.

Data is held in the NSW Data Analytic Centre's secure environment and protected in accordance with the NSW Cyber Security Policy. Access logs are monitored regularly for suspicious activity and unauthorised access.

Privacy and security arrangements for the HSDS are subject to ongoing monitoring and independent oversight. The PIDs require the Data Custodian to undertake an annual privacy and security compliance audit, and to notify the NSW Privacy Commissioner of any data breaches within 48 hours of confirmation. The Data Custodian must also report annually to the NSW Privacy Commissioner on the outcomes of compliance audits, data breaches occurred, complaints received, and the correctness of disclosures made in connection with the HSDS.

In the event of a data breach involving loss of, unauthorised access to or disclosure of Personal and Health Information, the response to the breach will be coordinated by the Project Team and managed in accordance with the HSDS Data Breach Policy. The HSDS Data Breach Policy provides guidance on relevant reporting and actions.

In accordance with the PPIP Act and HRIP Act, Personal and Health Information is to be kept as long as there is a lawful reason to do so. When there is no longer a lawful reason to keep the information, it will be securely disposed of or made non-identifiable as required in NSW privacy legislation

and the PIDs. The HSDS Retention and Disposal Policy provides further details on the procedures followed by the Project team.

## 4.5 Accessing and correcting Personal and Health Information

Each agency is required to provide relevant, up-to-date and accurate information for each refresh of the HSDS. Quality assurance and validation checks, such as data cleansing, are performed to ensure high quality and accurate linkage.

Under the PPIP Act and HRIP Act, individuals are allowed to access their Personal and Health Information without unreasonable delay or expense, and to update, amend or correct it where necessary.

Individuals can contact the Project Team to find out how to access or correct their Personal and Health Information collected for the HSDS using the contact details provided below.

<b>Contact</b>	Privacy Policy Officer, Project Team
<b>Email</b>	dataprivacy@facs.nsw.gov.au
<b>Postal address</b>	FACSIAR HSDS Governance and Privacy Team Ground Floor, 320 Liverpool Road Ashfield, NSW 2131

Please note that the Project Team is unable to identify individuals' Personal and Health Information collected for the HSDS as all identifiable personal information has been removed from the data. The Project Team will refer individuals' request to the agency or agencies that originally collected the information.

## 4.6 Making a privacy complaint (Internal Review)

Individuals have a right to seek an internal review if Personal and/or Health Information has been mishandled as part of the HSDS, in contravention of the Information Protection Principles and/or the Health Privacy Principles as modified by the PIDs.

Individuals must lodge an application for internal review in writing within six (6) months from the time of first becoming aware of the conduct that requires review.

To request an internal review individuals can fill out the Internal Review Form available at the end of this policy ([Appendix 1](#)) and send it to the Project Team at details provided in the form.

Individuals can also make a privacy complaint to the NSW Privacy Commissioner.



If individuals are unhappy with the outcome of the internal review, individuals can appeal the outcome to the NSW Civil and Administrative Tribunal.

Information on how to lodge a privacy complaint to the NSW Privacy Commissioner or the appeal is available on the Information and Privacy Commission NSW [website](#).

## 5 Roles and responsibilities

The main roles and responsibilities for the implementation of this policy are as follows:

### 5.1 Data Custodian

- Has overriding responsibilities of the data, including safe custody, access, use, storage and disclosure.
- Notifies the NSW Privacy Commissioner within 48 hours of confirming that any of the below have occurred:
  - any entity involved in the HSDS collected, used or disclosed Personal or Health Information in a way other than in accordance with the PIDs;
  - re-identification (deliberate or inadvertent) of de-identified data, other than in accordance with the PIDs;
  - a data breach involving Personal or Health Information.
- Reports annually on compliance with the PIDs to the NSW Privacy Commissioner regarding, among other things:
  - Data breaches (actual and potential) involving Personal Information or Health Information;
  - Results of the annual compliance audit.
- Approves analysts to provide Analytical Services and ensure they are contractually obliged to comply with the PPIP Act and HRIP Act as modified by the PIDs.

### 5.2 The Stronger Communities Data Partnership (SCDP)

- The Stronger Communities Data Partnership (SCDP) is the core governance group responsible for driving use of the Human Services Dataset in policy and delivery decision making, and improve return on investment. The group ensures the data regulatory environment, including security and privacy, are fit for purpose, and drive legislative reform as necessary.
- With the Data Custodian's agreement, significant issues or risks relating to the Project can be escalated to the SCDP for consideration or noting
- Notes any annual report on compliance with the Public Interest Directions.
- The SCDP reports to the Ministers and the Delivery and Performance Committee of Cabinet.

### 5.3 The Human Services Data Set Governance Advisory Committee (HSDGAC)

- Provides strategic advice and guidance to the Stronger Communities Data Partnership (SCDP), on governance of the HSDS, including compliance with relevant legislation and policies, and privacy and security requirements and processes.
- Ensures any data breaches or privacy concerns relating to the HSDS are responded to with appropriate monitoring and reporting mechanisms.
- Reviews all applications for access to and use of the data, where appropriate provides endorsement to the Data Custodian for approval.
- Reviews analytic findings before its public release.

### 5.4 The Project Team

- Develops, implements and reviews a data governance framework to provide oversight of the HSDS, including governance structure, policies and processes.
- In the event of a suspected or actual data breach, undertakes the responsibility of a Data Breach Response Team.
- Engages the Data Linkage Centre (currently CHeReL) to undertake data linkage for the HSDS and ensures they comply with the PPIP Act and HRIP Act as modified by the PIDs.
- Engages a Data Analytics Entity to undertake Analytical Services for the HSDS and ensures they are contractually obliged to comply with the current NSW Cyber Security Policy and safely accesses and stores relevant data.
- Reviews outputs and applications for use. Maintains register of HSDS access and use.
- Develops privacy training to be undertaken by all nominated analysts.
- Conducts an annual compliance audit to assess whether there are sufficient security systems and processes in place to protect Personal and Health Information that is collected, used and disclosed as part of the HSDS.
- Performs a Secretariat function for the Human Services Dataset Governance Advisory Committee (HSDGAC). Raises strategic and significant operational risks which may require reporting to the SCDP and Data Custodian.

### 5.5 The Project Privacy Officer

- Member of the FACSIAR HSDS Governance and Privacy Project Team, manages responses to privacy enquiries, complaints and internal reviews.

### 5.6 The Centre for Health Record Linkage

- Collects Personal and Health Information from agencies.

- Ensures Personal and Health Information is used in accordance with the PIDs.
- Discloses Identifier Information (a type of Personal Information) to the Australian Government Linkage Agency.
- Refers requests to access or correct Personal and Health Information received from individuals to the Project Privacy Officer.
- Retains Personal and Health Information for as long as it is required to determine if it belongs to persons within the Project Cohort.
- Protects Personal and Health Information from misuse, loss, unauthorised use or disclosure.
- Securely disposes of Personal and Health Information of persons determined to be outside the Project Cohort.
- Removes identifying information from Tier One Data and assigns PPNs to create Tier Two Data.
- Notifies the Project Team of any actual or perceived data breach that involved Personal and Health Information.
- Notifies the Project Team of any deliberate or inadvertent re-identification of de-identified data, other than in accordance with the PIDs.

## 5.7 The Australian Government Linkage Agency

- Collects Identifier Information (type of Personal Information) from the CHeReL to carry out data linkage services.
- Protects Identifier Information from misuse, loss, unauthorised use or disclosure.

## 5.8 The Data Analytics Entity

- Collects Tier Two Data from the CHeReL.
- Protects Tier Two Data from misuse, loss, unauthorised use or disclosure.
- Conducts privacy verification checks on Tier Two Data to ensure that it does not include any Personal or Health Information when disclosed to Approved Analysts for analysis, and to ensure that any statistical output derived from Tier Two Data does not include any identifying information prior to external release.
- Notifies the Project Team of any actual or perceived data breach that involved Personal and Health Information.
- Notifies the Project Team of any deliberate or inadvertent re-identification of de-identified data, other than in accordance with the PIDs.

## 5.9 Approved Analysts

- Use Tier Two Data only for Approved Purposes.
- Process Tier Two Data through the Information Protection Gates to ensure that no Personal information or Health information is included in

the Data prior to analysis and individuals cannot be re-identified in any data released to third parties.

- Process statistical outputs through the information protection to check for disclosure risk and ensure that no Personal information or Health information is included in the outputs before their external or public release.
- Adopt best practice privacy, security and de-identification practices as part of the information protection gates, including compliance with the NSW Cyber Security Policy.
- Notify the Project Team of any actual or perceived data breach that involved Personal and Health Information.
- Notify the Project Team of any deliberate or inadvertent re-identification of de-identified data, other than in accordance with the Public Interest Directions.

## 6 Monitoring, evaluation and review

It is the responsibility of the Project Team to monitor and update this policy when required. This policy will be reviewed every year and when any significant new information, legislative or organisational change warrants amendments to this document.

## 7 Support and advice

To obtain a hard copy of this policy or get advice and support about this policy please contact the Project Team using the contact details provided below.

<b>Email</b>	dataprivacy@facs.nsw.gov.au
<b>Postal address</b>	FACSIAR FACSIAR HSDS Governance and Privacy Ground Floor, 320 Liverpool Road, Ashfield, NSW 2131

If you are reviewing a printed version of this policy, please refer to [our website](#) to confirm that you are reviewing the most recent version of the policy. Following any subsequent reviews and approval this policy will be uploaded and all previous versions removed.

## 8 Definitions

The table below is a list of terms, keywords and/or abbreviations used throughout this document.

Definitions in this table were sourced from the PIDs unless stated otherwise.

Term	Definition
Analytical Services	The study, analysis, modelling, research or evaluation of Tier Two Data.
Approved Analysts	The Project Team or a person (including a researcher or analyst) that: <ul style="list-style-type: none"> <li>a) has been approved by the Data Custodian to provide Analytical Services for and on behalf of the Project Team; and</li> <li>b) is under a contractual obligation to comply with the PPIP Act and HRIP Act to the extent modified by a relevant Public Interest Direction.</li> </ul>
Approved Purpose	Any activity, task, work, step, process or measure that facilitates or enables the Project Objectives.
Australian Government Linkage Agency	A Commonwealth agency within the meaning of section 3(1) of the PPIP Act that provides data linkage services in accordance with the Public Interest Direction issued under section 41(1) of the PPIP Act.
Centre for Health Record Linkage (CHeReL)	The Centre for Health Record Linkage (CHeReL) has been engaged by the Project Team to undertake data linkage for the Project, in compliance with the NSW Cyber Security Policy.
Data Analytics Entity	A data analytics entity or function that is operated by a Public Sector Agency, which complies with the current NSW Cyber Security Policy, and that is engaged by the Project Team to undertake Analytical Services of the Project, such as the DAC (as defined in section 4 of the <i>Data Sharing (Government Sector) Act 2015</i> (NSW)) or such other entity that is under a contractual obligation to comply with the PPIP Act and HRIP Act to the extent modified by the Public Interest Directions.
Data Breach Policy	A policy outlining steps that should be followed to manage a data breach when it occurs in order to minimise the harm that the data breach could cause.
Data Custodian	The Agency, body or position designated with

Term	Definition
	<p>the custody of a specified Dataset or Information asset. The Data Custodian is primarily responsible for:</p> <ul style="list-style-type: none"> <li>• the development, management, care and maintenance of a specified Dataset or Information asset;</li> <li>• ensuring that all legal, regulatory and policy requirements are met in relation to the management of the specified Dataset or Information asset; and</li> <li>• determining the conditions for appropriate use, sharing and distribution of the specified Dataset or Information asset.</li> </ul> <p><i>Source: NSW Data and Information Custodianship Policy</i></p> <p>Currently, the Deputy Secretary Strategy, Policy and Commissioning is the Data Custodian of the Human Services Dataset.</p>
FACSIAR	Family and Community Services Insights, Analysis and Research
Health Information	The meaning of Health Information is given in section 6 of the HRIP Act. For the purpose of this policy, Health Information includes information set out in Part A of Schedule 1 of the <i>Public Interest Direction under section 62(1) of the HRIP Act</i> .
HRIP Act	<i>Health Records and Information Privacy Act 2002 (NSW)</i>
Human Services Data	Data or information (which may include Personal Information and Health Information) within a Participating Agency's or its contractors' or agent's records or system in connection with a Public Sector Agency's or other government agencies' interaction with, or provision of supports, services or programs to, an individual.
Human Services Dataset	The Human Services Dataset (HSDS) is a de-identified, longitudinal dataset that integrates administrative data collected on children and young people born after 1 January 1990, and includes their parents, carers and guardians. The data consists of service streams, outcomes and life events collected from across NSW government agencies and covers:

Term	Definition
	<ul style="list-style-type: none"> <li>• Child protection;</li> <li>• Housing;</li> <li>• Justice;</li> <li>• Health;</li> <li>• Mental health;</li> <li>• Alcohol and other drugs (AOD);</li> <li>• Parental risk indicators;</li> <li>• Commonwealth services.</li> </ul>
Identifier Information	A type of Personal Information, such as name and address.
Investment Model	<p>An actuarial model that uses the Human Services Dataset to forecast social outcomes and estimate the future cost of government service use.</p> <p><i>Adapted from the Forecasting Future Outcomes - Stronger Communities Investment Unit 2018 Insights Report.</i></p>
Participating Agency	A Public Sector Agency that collects or holds Human Services Data that is relevant to the HSDS and which has agreed to participate in the HSDS by disclosing Human Services Data to the Data Linkage Centre (currently CHeReL) in accordance with the Public Interest Directions.
Personal Information	<p>The meaning of Personal Information is given in section 4 of the PPIP Act. Personal Information means information or an opinion (including information or an opinion forming part of a database and whether or not recorded in a material form) about an individual whose identity is apparent or can reasonably be ascertained from the information or opinion.</p> <p>For the purpose of this policy, Personal Information includes the information set out in Part A of Schedule 1 of the Public Interest Direction made under <i>section 41(1) of the PPIP Act</i>.</p>
PPIP Act	<i>Privacy and Personal Information Protection Act 1998 (NSW)</i>
Project Team	The team established by the NSW Government to coordinate and lead the Project.

Term	Definition
Public Interest Direction	<p>Public Interest Direction made under section 41(1) of the PPIP Act or Public Interest Direction made under section 62(1) of the HRIP Act.</p> <p>Public Interest Directions are made by the NSW Privacy Commissioner to waive or make changes to the requirements for a public sector agency to comply with an Information Protection Principle or a Health Privacy Principle.</p>
Project	Their Futures Matter Project as described in the Public Interest Directions.
Project Cohort	Individuals born on or after 1 January 1990 (Primary Project Cohort) and individuals relevant to or related to those individuals; for example, family members, relatives, guardians and carers (Secondary Project Cohort).
Tier One Data	Human Services Data that has not been through any de-identification process to remove any Personal Information and Health Information.
Tier Two Data	Data derived from Tier One Data that has Identifier Information removed and been allocated a PPN in accordance with a relevant Public Interest Direction.
Tier Three Data	Aggregated Tier Two Data that has been through the Information Protection Gates process in accordance with a relevant Public Interest Direction.



## 9 Annexure 1: Internal Review Form

*This form has been adapted from the 'Privacy Complaint: Internal Review Application Form' published by the Information and Privacy Commission NSW (© State of New South Wales through the Information and Privacy Commission NSW 2015) under a Creative Commons Attribution 4.0 International License.*

This is an application for review of the conduct of a public sector agency in relation to the Human Services Dataset. This application is made under (please tick one):

- [s.53 of the Privacy and Personal Information Protection Act 1998 \(PPIP Act\)](#)  
 [s.21 of the Health Records and Information Privacy Act 2002 \(HRIP Act\)](#)

<b>1.</b>	Your full name:
<b>2.</b>	Your postal address:
	Telephone number:
	Email address:
<b>3.</b>	If the complaint is on behalf of someone else, please provide their details
	Full name:
	Postal address:
	Telephone number:
	Email address:
	What is your relationship to this person (e.g. parent)?
	Please include details of your authority to act or make the complaint on behalf of the person you have named above.
	Is the person capable of making the complaint by himself or herself? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure

4.	What is the specific conduct you are complaining about? (See footnote <sup>1</sup> for explanation of “conduct”)
5.	<p>Please tick which of the following describes your complaint: (you may tick more than one option)</p> <p><input type="checkbox"/> collection of my personal or health information</p> <p><input type="checkbox"/> security or storage of my personal or health information</p> <p><input type="checkbox"/> refusal to let me access or find out about my own personal or health information</p> <p><input type="checkbox"/> accuracy of my personal or health information</p> <p><input type="checkbox"/> use of my personal or health information</p> <p><input type="checkbox"/> disclosure of my personal or health information</p> <p><input type="checkbox"/> other</p> <p><input type="checkbox"/> unsure</p>
6.	When did the conduct occur (date)? (Please be as specific as you can)
7.	When did you first become aware of this conduct (date)? (Please be as specific as you can about how and when you first became aware of the conduct. Please include any action that you took at the time)
8.	<p>You need to lodge this application within six months of the date at Q.8.</p> <p>If more than six months has passed, you will need to ask the agency for special permission to lodge a late application. Please explain why you have taken more than six months to make your complaint (for example: I had other urgent priorities – list them, or while the conduct occurred more</p>

<sup>1</sup> “Conduct” can include an action, a decision, or even inaction by the agency. For example the “conduct” in your case might be a decision to refuse you access to your personal information, or the action of disclosing your personal information to another person, or the inaction of a failure to protect your personal information from being inappropriately accessed by someone else

	<i>than six months ago, I only recently became aware of my privacy rights, etc.):</i>
9.	What effect did the conduct have on you?
10.	What effect might the conduct have on you in the future?
11.	What would you like to see the agency do about the conduct? <i>(For example: an apology, a change in policies or practices, your expenses paid, damages paid to you, training for staff, etc.)</i>

I understand that this form will be used by the Project Privacy Officer to process my request for an internal review. I understand that details of my application will be referred to the NSW Privacy Commissioner in accordance with: section 54(1) of the *Privacy and Personal Information Protection Act*; or section 21 of the *Health Records and Information Privacy Act*; and that the NSW Privacy Commissioner will be kept advised of the progress of the internal review.

Your signature: \_\_\_\_\_

Date: \_\_\_\_\_

**SEND THIS FORM TO THE PRIVACY OFFICER USING THE DETAILS BELOW:**

**Email:** [dataprivacy@facs.nsw.gov.au](mailto:dataprivacy@facs.nsw.gov.au)

**OR**

**Postal address:** FACSIAR, HSDS Privacy and Governance Team, Ground Floor, 320 Liverpool Road, Ashfield, NSW 2131

**KEEP A COPY FOR YOUR RECORDS.**