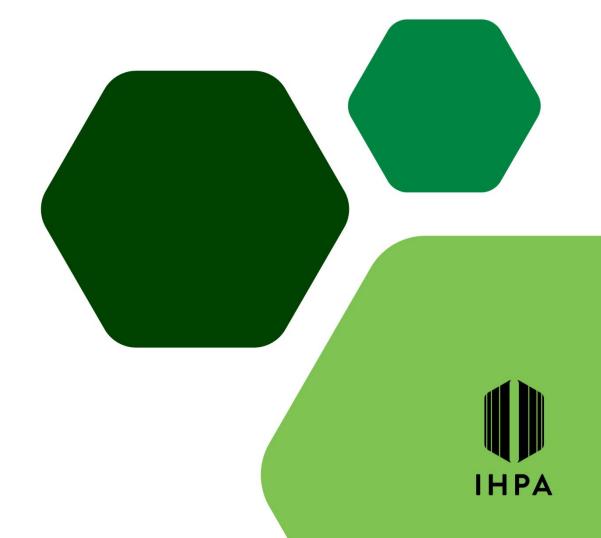
Data Access and Release Policy

May 2022



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Acronyms and abbreviations

ABF Activity based funding

AIHW Australian Institute of Health and Welfare

CEO Chief Executive Officer

FOI Act Freedom of Information Act 1982 (Cwlth)

HCEF Health Chief Executives Forum¹

HMM Health Ministers' Meetings²

IHPA Independent Hospital Pricing Authority

IPS Information Publication Scheme

NHCDC National Hospital Cost Data Collection

NHR Act National Health Reform Act 2011 (Cwlth)

NMDS National Minimum Data Set

NBEDS National Best Endeavours Data Set

The Addendum Addendum to the National Health Reform Agreement 2020–25

This Policy Data Access and Release Policy

SDMS Secure Data Management System

¹ The Health Chief Executives Forum has been established as the advisory and support body to the Health Ministers' Meetings, and serves as the replacement for the Australian Health Ministers' Advisory Council.

² The Health Ministers' Meetings, comprised of all Australian health ministers, has been established to consider matters previously brought to the Council of Australian Governments Health Council, including matters relating to the national bodies. The Health Ministers' Meetings serves as the replacement for the Council of Australian Governments Health Council.

Definitions

Aggregate data Summary data held by the Independent Hospital Pricing Authority (IHPA) or on

IHPA's behalf that does not contain information which may enable the

identification of an individual or an organisation.

Aggregation The combination of related categories, usually within a common branch of a

hierarchy, to provide information at a broader level at which detailed

observations are taken.

Data Representation of facts, concepts or instructions³.

Data set Any organised collection of data.

Metadata Information about how data is defined, structured and represented. It can

provide meaning and context to data by describing how data is captured and the business rules for collecting data. It can also assist in the interpretation

of data3.

Pricing Authority The governing body of IHPA established under the *National Health Reform*

Act 2011 (Cwlth) (NHR Act).

Protected data Data obtained for the purpose of section 131 of the NHR Act and clause B3

of the National Health Reform Agreement.

Includes all unit record data and protected aggregate data.

Protected aggregate data

Aggregate data that has been masked to prevent identification of an individual or organisation. This must be made on a case-by-case basis by reviewing the data to determine what information or conclusions the reader may draw from that

data.

Protected Pricing Authority information

As defined in section 5 of the NHR Act, information that:

- was obtained by a person in the person's capacity as an official of the Pricing Authority; and
- relates to the affairs of a person other than an official of the Pricing Authority.

Unit record dataData held by IHPA or on IHPA's behalf, which refers to a single event associated with an individual or an organisation (such as an episode of care, a phase of

care or a service event).

Unit record data may enable the identification of an individual or an organisation.

³ Australian Institute of Health and Welfare. Metadata Online Registry - About metadata. Available at: http://meteor.aihw.gov.au/content/index.phtml/itemId/268284.

1. Executive summary

1.1 Background

The National Health Reform Act 2011 (Cwlth) (NHR Act) and the Addendum to the National Health Reform Agreement 2020–25 (the Addendum) require the Independent Hospital Pricing Authority (IHPA) to publicly report on its activities and disclose information in certain circumstances. IHPA is also bound by other legislative requirements including the *Freedom of Information Act 1982* (Cwlth) (FOI Act), the *Privacy Act 1988* (Cwlth) (Privacy Act) and the Information Publication Scheme (IPS) which provide a legislative framework for disclosure of government information to the public.

IHPA recognises that access to high quality, nationally consistent health data is essential for the conduct of research and analysis and to inform the development of policies for improving health outcomes for all Australians.

Pursuant to its functions outlined in the NHR Act, IHPA collects hospital data that contains demographic information, clinical information, the nature of care provided and costs. This data is subject to secrecy provisions contained in the NHR Act which relate to protected Pricing Authority information.

1.2 Purpose

The purpose of the *Data Access and Release Policy* (this Policy) is to outline the principles and processes adopted by IHPA in the discretionary access and release of data collected under the NHR Act and Addendum by:

- using a consistent approach in releasing data
- complying with the legislative requirements, in particular Part 4.14 of the NHR Act and the Australian Privacy Principles contained within the Privacy Act (where applicable)
- assessing risks associated with the release of data based on a set of principles.

IHPA is committed to transparency and open access to data, consistent with the objectives of the NHR Act, FOI Act, Privacy Act and IPS. However, this is subject to IHPA's obligation to respect and maintain confidential, commercially valuable and personal information.

This Policy provides guidance as to how IHPA will determine whether to release data. This Policy does not address data requests where IHPA is required by law to release data, though it refers to the circumstances where disclosures may occur and relevant IHPA procedures.

1.3 Review

The Pricing Authority and Chief Executive Officer (CEO) of IHPA will review this Policy, including associated documentation, annually or as required.

This Policy was last reviewed in May 2022.

2. Types of data release

This Policy is concerned with the release of data to researchers and to certain specified bodies, agencies or persons only. As outlined in section 214 of the NHR Act, IHPA may disclose protected Pricing Authority information for purposes relating to the performance of its functions. This would typically occur where IHPA engages a contractor or consultant. Management of information releases to contractors or consultants providing services in performance of IHPA's functions is outlined in the *Consultant Access to IHPA Protected Data Rules*.

An overview of the types of data held by IHPA is provided at **Appendix A**.

A significant amount of information held by IHPA, including information regarding its functions, is already available to the public or is regularly released either voluntarily or due to public reporting obligations. **Appendix B** includes a list of IHPA publications and publicly available information, as required by law.

The release of data by IHPA is subject to other IHPA policies and processes such as the IHPA Freedom of Information Policy.

2.1 Release of data to different parties

The FOI Act, the Australian Privacy Principles contained within the Privacy Act, and the IPS provide a legislative framework for disclosure of government information to the public. For information on the requirements placed on agencies such as IHPA covered by the FOI Act, refer to the IPS.

2.2 Release of data to conduct research

Section 221 of the NHR Act states that protected Pricing Authority information may be released to an agency, body or person if the Chair of the Pricing Authority is satisfied that this information will assist an agency, body or person to conduct research. The Chair of the Pricing Authority may delegate this power to the CEO of IHPA under section 221(2) of the NHR Act.

In line with the National Health Information Agreement, IHPA understands a researcher to be a person or organisation that can demonstrate they are undertaking research to improve Australian health policy. The Chair of the Pricing Authority or CEO of IHPA will also adhere to the principles detailed in Chapter 3 of this Policy to determine if a data release is fit for research purposes.

IHPA will not release data to third parties if:

- it may risk patient confidentiality
- the data is commercial-in-confidence; or
- the data may lead to concerns of health care professional confidentiality.

IHPA will consider data release requests from researchers located outside of Australia on a case-by-case basis.

2.3 Release of data to certain bodies, agencies or persons

Sections 218 and 220 of the NHR Act and clause B77 of the Addendum set out principles under which data collected by IHPA may be shared with other National Health Reform Agreement agencies and other Commonwealth and state and territory government departments and agencies.

Under section 220 of the NHR Act, data can be released to enable or assist any of the following agencies, bodies or persons to perform or exercise any of the functions or powers of the agency, body or person, subject to the conditions in section 220 of the NHR Act:

- the Australian Commission on Safety and Quality in Health Care
- the Administrator of the National Health Funding Pool
- the National Health Funding Body
- the Health Ministers; Meetings (HMM)
- the Health Chief Executives Forum (HCEF)
- the Australian Institute of Health and Welfare (AIHW)⁴
- the Australian Statistician
- a state or territory government body that has functions relating to health care
- an agency, body or person specified in a legislative instrument made by the Minister with the agreement of National Federation Reform Council⁵.

The Chair of the Pricing Authority may delegate any or all of his or her functions and powers to the CEO of IHPA (section 224, NHR Act). Since 2013, the CEO of IHPA has power of delegation for data releases to the above specified agencies, bodies or persons.

All data releases made in accordance with this Policy are regularly reviewed by the Pricing Authority.

⁴ The National Health Performance Agency has been dissolved, with its activities and functions transferred to the Australian Institute of Health and Welfare.

⁵ The Council of Australian Governments has been dissolved. <u>The National Federation Reform Council</u>, led by National Cabinet, has been established as its replacement to consider matters previously brought to the Council of Australian Governments.

3. Principles for data access and release

Where IHPA receives a request for data, IHPA will consider the following principles in determining if the data can be released. All principles outlined in **Table 1** must be satisfied for data to be released.

Table 1. Data access and release principles and mechanisms

Data access and release principles	Data release mechanism	
1. Fit for purpose		
2. Compliant with legislation	The data release must comply with legislation dealing with privacy, secrecy, consent, commercial-in-confidence arrangements and access to freedom of information. Relevant legislation includes, but is not limited to the: • Public Governance and Performance Accountability Act 2013 (Cwlth) • National Health Reform Act 2011 (Cwlth) • Privacy Act 1988 (Cwlth) • Freedom of Information Act 1982 (Cwlth) • Public Service Act 1999 (Cwlth) • Archives Act 1983 (Cwlth) • Electronic Transactions Act 1999 (Cwlth) • Evidence Act 1995 (Cwlth) • Crimes Act 1914 (Cwlth) • Ombudsman Act 1976 (Cwlth). Any information provided to IHPA under a confidentiality agreement will be treated as confidential and not released on a discretionary basis.	

Data access and	Data release mechanism	
release principles	In general terms, IHPA is obliged to ensure the data being released is:	
	accurate	
	 used only for the purpose for which it was collected unless provided for by law 	
	not disclosed unless provided for by law and meets the principles outlined in this table	
	in accordance with legislative requirements and is done in a way that ensures privacy and protects patient confidentiality.	
3. Suitable quality for use	In assessing the suitability of data quality for use, the following will be considered:	
	accuracy and reliability	
	 agreed definitions, methodologies, measurement techniques and reporting formats 	
	limitations of the data, including suitable caveats, are clarified	
	reports and releases are accompanied by metadata.	
4. Suitable for release	Under this Policy, data will be withheld from release in additional circumstances, including:	
	commercial-in-confidence – contains information that is commercial-in-confidence or otherwise commercially sensitive	
	 patient confidentiality concerns – data that, if released, may be in breach of patient confidentiality. Section 279(2) of the NHR Act states that IHPA must not publish or disseminate information that is likely to enable the identification of a particular patient 	
	 health care professional confidentiality concerns – data that, if released, may impact on confidential issues related to health care professionals 	
	access outside of Australia – in accordance with the NHR Act, IHPA will not release data to third parties based outside Australia.	
5. Resource availability	The <i>Public Governance and Performance Act 2013</i> (Cwlth) requires IHPA be governed in a way that promotes the proper use of public resources and achievement of IHPA's functions.	
	There are various tests that will be applied to guide decisions on whether to commit resources. These may include assessment of the following:	
	public benefits exceed IHPA resource costs	
	ability to meet the request in the timeframes stated	
	 reasonableness of the requests on IHPA resources given other priorities 	
	consequences of not providing the data.	

4. Data access and release process

IHPA has a systematic process to manage access and release of data. The following sections outline the processes and procedures for requesting data, considering requests and releasing data.

4.1 Submitting a data request

Requests for data access and release should be addressed in writing to the CEO of IHPA using the 'Research Data Request Form' at **Appendix C**.

As a guide, the following matters need to be included in the written request:

- aim/s
- critical dates, including for data analysis and publication of any planned deliverables
- data services sought (for example, data extraction)
- data variables of interest
- data collection involved (for example, costing data, activity data)
- time periods of interest
- requestor contact details
- details of all parties who are requesting access to the data
- any other information that may support the application.

4.2 Consideration of data requests

IHPA will consider the principles outlined in Chapter 3 of this Policy when determining whether the data will be released.

IHPA may request an applicant review their request for data if it does not fully comply with the data access and release principles.

Consultation with jurisdictions

IHPA will inform jurisdictions in writing of a request for data access and release via its Jurisdictional Advisory Committee, and provide a 14-day consultation period for jurisdictions to comment on a proposed data release.

As part of the consultation, IHPA will advise jurisdictions of the requested data specifications, the source of the data request, relevant parties who will have access to the data and the type of ethical approval obtained (if applicable). This information will be accompanied by a copy of the completed 'Research Data Request Form'. Jurisdictions will also be advised of any data manipulation IHPA has undertaken or plans to undertake prior to release (for example, masking of small cell areas).

IHPA will liaise with jurisdictions and the applicant should any issues be raised during the consultation process. Following consultation, IHPA may seek additional information from the applicant, establish further access requirements or prevent data access.

All jurisdictions will be advised of IHPA's decision via updates through Jurisdictional Advisory Committee meetings. Some occasions may warrant IHPA outlining the decision directly to a jurisdiction in writing.

4.3 Amending a data request

IHPA may make changes to an original request for data in an effort to protect patient confidentiality. Changes may include de-identification of data and masking of small cell areas. IHPA will advise applicants of any changes to original requests.

De-identification of data

IHPA will amend certain fields to minimise the risk of re-identification of patients, including but not limited to replacing date of birth with age at date of admission; replacing date of separation with month of separation; and substituting postcode with the Australian Statistical Geography Standard region unless requestors demonstrate a strong requirement for the inclusion of these fields. IHPA will amend additional fields where the requested data set has a large number of variables that in combination may re-identify patients.

Small cell area

Data will not be released if there is a threat to privacy and confidentiality or if the data is of doubtful quality.

It is impracticable to have a fixed rule as minimum cell size is a function of the sensitivity and quality of data. However, IHPA will refer to the AIHW policies in regards to minimum cell size. A range of methods may be used to assist in determining minimum cell size to ensure the lowest possible disclosure risk, including⁶:

- cell zeroing
- cell suppression
- collapsing cells
- recoding variables
- rounding
- data swapping
- controlled tabular adjustment.

It should be noted that all jurisdictions are bound by their own data release policies and privacy legislation, which may place additional requirements on small cell identification.

4.4 Ethics approvals for data requests

It is at the discretion of IHPA to determine whether a request for data should be accompanied by clearance from an approved human research ethics committee.

⁶ National Health Information Standards and Statistics Committee. Guidelines for the Disclosure of Secondary Use Health Information for Statistical Reporting, Research and Analysis (2017). Available at: https://www.aihw.gov.au/getmedia/d15f8bf7-f29f-406a-a27d-41f483b17ff1/Guidelines-Use-and-disclosure-of-secondary-health-information-endorsed-15-June-2017.pdf.aspx.

IHPA will notify applicants without ethics approval if it will need to be obtained. This can occur any time prior to the release of data.

Further details and advice about what constitutes research which requires ethical review is available from the National Health and Medical Research Council.

4.5 Requirements prior to data being released to conduct research

All researchers who will have access to data will be required to:

- Sign a Deed of Confidentiality agreeing to any caveats and limitations on use of any information provided for the purposes of research.
- Acknowledge that IHPA takes no responsibility for the accuracy and completeness of the data, and the outcomes related to its use.
- Agree to use the source data and any information provided by IHPA as confidential, for the approved research use only.
- Must not, without the prior consent of IHPA, disclose any source data or information provided by IHPA to a third party, noting that before giving such consent, IHPA will consider advice from the data custodian.
- Only use the data for the purposes of research and not for any other purpose unless otherwise approved by IHPA and in line with the requirements of this Policy.
- Agree to make no attempt to link the data with any other data source/s that may result in patient re-identification.
- Comply with the conditions of use in respect of the data provided and note that they will continue indefinitely.
- Provide copies of any key deliverables or work products as a result of the research at least two months prior to them being made publicly available. IHPA will advise jurisdictions of any intended publication of research that has included jurisdictional data.
- Adhere to any other conditions which IHPA deems fit.

In most instances, IHPA will supply data through the Secure Data Management System (SDMS). In order to access data through the SDMS, researchers will also be required to:

- Provide a copy of a National Police Check as per IHPA's *Information Security Policy*.
- Undergo IHPA Security Training over the phone.
- Complete an SDMS user access form.

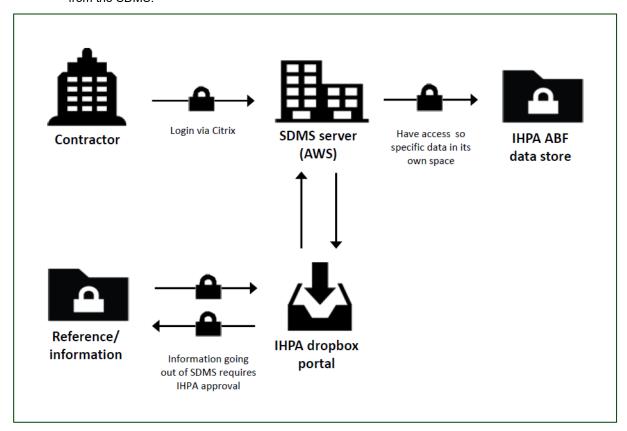
4.6 Assessment of risks associated with release of data to conduct research

IHPA will assess the application based on the requirements of this Policy, complete a risk assessment and make recommendations for consideration by the CEO of IHPA.

4.7 Data access model

IHPA facilitates access to IHPA data via the SDMS, a secure online platform that does not allow for the direct download of data. SDMS access can be made available at IHPA's office in Sydney or offsite using the third party supplier's own hardware. The data access model displayed in **Figure 1** outlines this process.

Figure 1. IHPA's protected data access model: activity based funding (ABF) data that is collected and stored by IHPA may be accessed securely via the SDMS. The IHPA dropbox portal allows users to securely download data from the SDMS in a number of file formats. IHPA approval is required for all file downloads from the SDMS.



Alternatives to this model require justification and a risk assessment. These requests must be approved by the CEO of IHPA or the Chair of the Pricing Authority in writing.

4.8 Data storage and transfer rules

IHPA will grant access to data in line with the IHPA protected data access model. The permissions and security profiles configured within the SDMS provide additional restrictions on the storage and transfer of data, as such the transfer of any data to or from the SDMS requires approval from IHPA. This approval process requires the applicant to complete an Assurance Statement on each occasion data is being transferred out of the SDMS, which asserts the file does not include original data sourced from IHPA.

4.9 End of data access

IHPA will ensure that access to the SDMS by third parties is terminated at the end of the access period.

4.10 Requests for extended access to data

Where the CEO of IHPA or the Chair of the Pricing Authority has approved access to data, the third party may only access this data over a period of 24 months. Where the third party requires access to the data for a longer period than 24 months, a request should be made to IHPA for an extension, specifying the length of the extension and why it is required.

The CEO of IHPA will consult with all jurisdictions in writing on the request for extended access to the data and determine whether extended access is approved. Extended access may be temporarily approved by IHPA while this consultation process occurs.

4.11 Complaint process

Should a third party want to raise a complaint about IHPA's decision to release data, the following process should be followed:

- Requesting party to raise the complaint in writing to the attention of the CEO of IHPA.
- IHPA will acknowledge the complaint in writing.
- IHPA will investigate the complaint and aim to resolve factual issues and consider options for resolution.

Any systemic issues that arise as a result of the complaint or enquiry will be considered by IHPA.

5. Inadvertent release of data

IHPA's <u>Privacy Policy</u> which is underpinned by the *Privacy Act 1988* (Privacy Act) outlines its approach for handling data breaches.

In the event of an inadvertent release of protected Pricing Authority information, IHPA will adhere to the response procedures outlined in the <u>Notifiable Data Breaches</u> (NDB) scheme in Part IIIC of the Privacy Act.

IHPA has developed an internal Data Breach Response Plan which outlines IHPA's procedures for managing data breaches in accordance with the NDB. Upon approval of a data request, IHPA will provide security training to the third party which includes an overview of IHPA's Data Breach Response Plan.

Appendix A: Data held by IHPA

Detailed in Table 2 is a list of data collections held by IHPA.

Table 2. List of data collections held by IHPA

Data held by IHPA	Specifications
Hospital cost data	The National Hospital Cost Data Collection (NHCDC) specifications for the current round are available here . Applicants can also consult the hospital Patient Costing Standards (which outlines how hospital products should be costed) and the Independent Financial Review (which reviews compliance with the Australian Hospital Patient Costing Standards).
Admitted patient activity	The Admitted patient care National Minimum Data Set (NMDS) for acute patients and subacute patients, with additional data items in the Admitted sub-acute and non-acute hospital care National Best Endeavours Data Set (NBEDS).
Emergency patient activity	The Non-admitted patient emergency department care NMDS for emergency department patients and Emergency service care NBEDS for emergency service patients.
Non-admitted patient activity	The Non-admitted patient NBEDS for non-admitted patients and the Non-admitted patient care aggregate NBEDS for aggregate data on non-admitted services.
Mental health care patient activity	The Activity based funding: Mental health care NBEDS.
Teaching and training activity	The <u>Hospital teaching, training and research activities NBEDS</u> . Note that research activities were added to this Data Set Specification in 2015–16.
Sentinel events data	Data on sentinel events, funded by states and territories, that are associated with Australian public hospitals.
Coronavirus disease 2019 (COVID-19) data	Data on activity that is attributed to the diagnosis and treatment of Medicare-eligible patients with COVID-19 or suspected of having COVID-19.
Individual Healthcare Identifier data	The Individual Healthcare Identifier NBEDS.

Appendix B: IHPA publications and publicly available information

IHPA publications and publicly available information are outlined in **Table 3**.

Table 3. IHPA external publications and publicly available information

Publications and publicly available information

- National Efficient Price Determination
- National Efficient Cost Determination
- National Pricing Model Technical Specifications
- National weighted activity unit calculators
- Pricing Framework for Australian Public Hospital Services
- IHPA Work Program and Corporate Plan
- IHPA Three Year Data Plan
- Data Request Specifications
- NHCDC Public Sector Report and cost weight tables
- NHCDC Private Sector Report and cost weight tables
- Independent Financial Review of the NHCDC
- IHPA Annual Report
- Data Compliance Policy
- Data Compliance Reports
- Indexed List of Agency Files (Harradine report)
- Contracts on Austender and published in accordance with Senate Order on Departmental and Agency Contracts (Murray Motion)
- Reports on classification development and costing studies
- IHPA policies, such as the Confidential Data Management Policy

Appendix C: Research Data Request Form



Overview

The Independent Hospital Pricing Authority (IHPA) recognises that access to high quality, nationally consistent, health data is essential for the conduct of research and analysis and to inform the development of policies for improving health outcomes for all Australians.

If you would like to request data from IHPA, please complete the following form addressed to:

Chief Executive Officer

Independent Hospital Pricing Authority

PO Box 483

Darlinghurst NSW 1300

An editable PDF version of this application form is also available on the IHPA website.

IHPA will assess your request and advise you if any further information is required. If you have any queries with regards to the information request process or your request, please call 02 8215 1100.

Your name (please print clearly)		
Your organisation		
Detail your company, agency, university, etc.		

Your position		
Detail your current position, student details and	supervisor (if relevant).	
Your email address		
Your phone number		
Names, positions and contact details of other people who will have access to the data within your organisation (please print clearly)		
Information request description		
Detail the information / data set requirements, etc. Please provide as much detail as possible around the data sought, to enable IHPA to fully assess its ability to meet your request.		
Time period/s of interest		
Start date:	End date:	

Intended use of information
Detail the research project description including purpose, duration, potential benefits of the research, audience, etc., and where possible, please include information on intentions to publish or present data such as in academic journals and/or at conferences.
Note the advanced notice periods required prior to the publication of any deliverables, as outlined in the <i>Data Access and Release Policy</i> .
Linking of data
Do you intend to link the data currently being requested to any other data sources?
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Ethics clearance		
Please provide evidence of ethics approval, if granted.		
Timeline for project completion		
Detail of proposed project timeline including accessing IHPA data, conducting analysis, deadlines for publication or PhD completion etc.		
·		

Declaration by applicant

I make this data request on the basis that the details in this form are true and accurate.

I agree to the following caveats and limitations on use of any data provided to me for the purposes of research:

- Acknowledge that IHPA takes no responsibility for the accuracy and completeness of the data, and the outcomes related to its use
- Agree to use the source data and any information provided by IHPA as confidential, for the approved purpose only
- Must not, without the prior consent of IHPA, disclose any confidential information provided by IHPA to a third party or those not approved on the consent form
- Must not use the confidential information for commercial gain
- Only use the confidential information for the purposes of research and not for any other purpose unless otherwise approved by IHPA
- Comply with the conditions of use in respect of the confidential information provided and note that they will continue indefinitely
- Consider the IHPA data notes which outline the data quality issues, costing notes and other considerations when analysing the data contained in the confidential information
- Agree not to make any attempt to link the data contained in the confidential information with any other data source/s without IHPA authorisation
- Agree not to use, publish or disseminate any data in a way that might enable the identity
 of health professionals, hospitals or Local Hospital Networks to be ascertained from the
 confidential information
- Agree to provide IHPA with advanced copies of any deliverables resulting from the use of IHPA data at least two months prior to their publication
- Agree to notify IHPA immediately of any breaches of this Deed or the caveats and limitations on use
- Adhere to any other conditions which IHPA deems fit.

Signature of applicant/s (include signatures of all individuals seeking access to the data)	Date
Students, including PhD candidates, must have their research supervisor complete below. Signature of supervisor	Date

Independent Hospital Pricing Authority

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