Independent Hospital Pricing Authority

Data Access and Release Policy

May 2020

IHPA

Data Access and Release Policy – Version 4.3 May 2020

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Acronyms and abbreviations

AIHW	Australian Institute of Health and Welfare
ASGS	Australian Statistical Geography Standard
CEO	Chief Executive Officer
COAG	Council of Australian Governments
DSS	Data Set Specification
FOI Act	*Freedom of Information Act 1982 (Cwlth)*
IHPA	Independent Hospital Pricing Authority
IPS	Information Publication Scheme
Murray Motion	Senate Order on Entity Contracts
NHCDC	National Hospital Cost Data Collection
NHR Act	*National Health Reform Act 2011 (Cwlth)*
NHRA	National Health Reform Agreement
NMDS	National Minimum Data Set
NBEDS	National Best Endeavours Data Set
PGPA Act	*Public Governance and Performance Accountability Act 2013 (Cwlth)*
The Policy	IHPA *Data Access and Release Policy*
SDMS	Secure Data Management System

Definitions

Aggregate data	Summary data held by 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 to that at which detailed observations are taken.
Data	Representation of facts, concepts or instructions[1].
Dataset	Any organised collection of data.
Metadata	Structured description of the content, quality, condition or other characteristics of data. Metadata needs to accompany data; otherwise the data being transmitted or communicated cannot be understood[1].
Pricing Authority	The governing body of IHPA established under the *National Health Reform Act 2011 (Cwlth)*.
Protected data	Data obtained for the purpose of Section 131 of the *National Health Reform Act 2011* (Cwlth) 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 *National Health Reform Act 2011* (Cwlth), information that: • Was obtained by a person in the person's capacity as an official of the Pricing Authority; and

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

- Relates to the affairs of a person other than an official of the Pricing Authority.

Unit record data	Data 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.

1. Executive summary

1.1 Background

The National Health Reform Agreement (NHRA) and the *National Health Reform Act 2011* (NHR Act) 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* (FOI Act), the *Privacy Act 1988* (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.

IHPA does not collect or store personal patient information including name, address, phone number or Medicare number.

1.2 Purpose

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

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.

1.3 Scope

The Policy applies to requests for release of data under the NHR Act and NHRA. The Policy provides guidance as to how IHPA will determine whether to release data.

The Policy does not deal with 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.

1.4 Objectives

The overall objective of the Policy is to ensure that IHPA is:

- 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 on the basis of a set of principles.

1.5 Review

The Chief Executive Officer (CEO) of IHPA will review the Policy, including associated documentation, annually or as required. This review will ensure the Policy remains current to sufficiently support IHPA in managing the risks associated with data access and release.

The Policy was last reviewed in May 2020.

2. Types of data release

An overview of the types of data held by IHPA are listed in 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 lists 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.

This Policy is concerned with 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 also 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 covered in the *Consultant Access to IHPA Protected Data Rules*.

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 what requirements this places on agencies covered by the FOI Act like IHPA, refer to the IPS.

Release of data to conduct research

Part 4.14, section 221 of the NHR Act states that protected Pricing Authority data may be released to an agency, body or person if the Chair of the Pricing Authority is satisfied that this data 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 for Data Access and Release* detailed in Chapter 3 of the Policy to determine if a release is fit for research purposes.

IHPA will not release data to third parties based outside Australia. Other conditions that would prevent IHPA from releasing data include if the data may risk patient confidentiality (as detailed in section 279(2) of the NHR Act), the data is commercial-in-confidence or if the data may lead to health care professional confidentiality concerns.

Release of data to certain bodies, agencies or persons

Sections 218 and 220 of the NHR Act and clause B97 of the NHRA sets out principles under which data collected by IHPA may be shared with other NHRA 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:

- National Health Performance Authority (no longer in existence)
- Australian Commission on Safety and Quality in Health Care
- the Administrator of the National Health Funding Pool
- National Health Funding Body

- the Council of Australian Governments (COAG) Health Council
- The Australian Health Ministers' Advisory Council
- The Australian Institute of Health and Welfare
- The Australian Statistician
- A state/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 COAG.

  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 Chair of the Pricing Authority may delegate any or all of his or her functions and powers to the CEO of IHPA (s224, NHR Act). Since 2013, the CEO of IHPA has power of delegation for data releases to the above specified agencies, bodies or persons.

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 will be released. All principles outlined in Table 1 must be satisfied in order 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	Fit for purpose refers to the closeness of correspondence between the characteristics of the data requested and its intended purpose. A poor fit means that the data is unlikely to serve the intended purpose of those requesting the data. IHPA will evaluate information supplied by the applicant in the Research Data Request Form at Appendix C to determine if the data request aligns with the intended use of information. Where required, IHPA will provide appropriate caveats around data to enable users to reach an informed view about the limitations of any data provided. IHPA will ensure that any caveats or limitations on the data that have been identified by the data custodian (i.e. states and territories) will be provided together with the data.
2. Compliant with legislation	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 1975 (Cwlth)* Any information provided to IHPA under a confidentiality agreement will be treated as confidential and not released on a discretionary basis. 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 *Data Access and Release Principles* • in accordance with legislative requirements and is done in a way that ensures privacy and protects patient confidentiality.

Table 1. Data access and release principles and mechanisms (continued)

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 the Policy, data can be withheld from release in certain 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 *Public Governance and Performance Act 2013* (PGPA Act) 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 section outlines the processes and procedures for requesting data, considering requests and releasing data.

4.1 Submitting a request for data

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

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

- aims(s)
- critical dates
- data services sought (e.g. data extraction)
- data variables of interest
- data collection involved (e.g. costing data, activity data)
- time periods of interest
- requestor contact details
- any other information the applicant may feel is relevant to the application.

4.2 Consideration of requests

IHPA will consider the *Data Access and Release Principles* outlined in Chapter 3 of the Policy when determining whether the data will be released.

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

As part of the consultation, IHPA will advise jurisdictions of the requested data specifications, the source of the data request, all or 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 (including small cell areas, etc.).

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, place further access requirements or prevent data access.

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

4.3 Amending of requests for data

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 (ASGS) region unless requestors demonstrate a strong requirement for the inclusion of these fields. IHPA will amend additional fields where the requested dataset has a large number of variables that in combination may re-identify patients.

Small cell area

Data in a data cell shall 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 Australian Institute of Health and Welfare (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 including[2]:

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

It should be noted that all jurisdictions are tightly 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.

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.

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[2] 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.

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 (N.B. Before giving such consent, IHPA will consider advice from the data custodian)
- May only use the data solely 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
- Agrees 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 prior to 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 criminal record check as per IHPA's *Obtaining and dealing with National Police Certificates Policy*
- Undergo IHPA Security Training either in person or over the phone
- Sign a 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 the Policy, complete a risk assessment and make recommendations for consideration by the CEO of IHPA and Chair of the Pricing Authority.

In instances where IHPA has supplied data via devices including on USBs, hard drives and laptop computers, researchers will also be required to complete the Third Party ICT and Data Management Controls questionnaire every three months.

4.7 Data Access Model

IHPA facilitates access to IHPA data via 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 suppliers own hardware. The data access model displayed in Figure 1 documents this process.

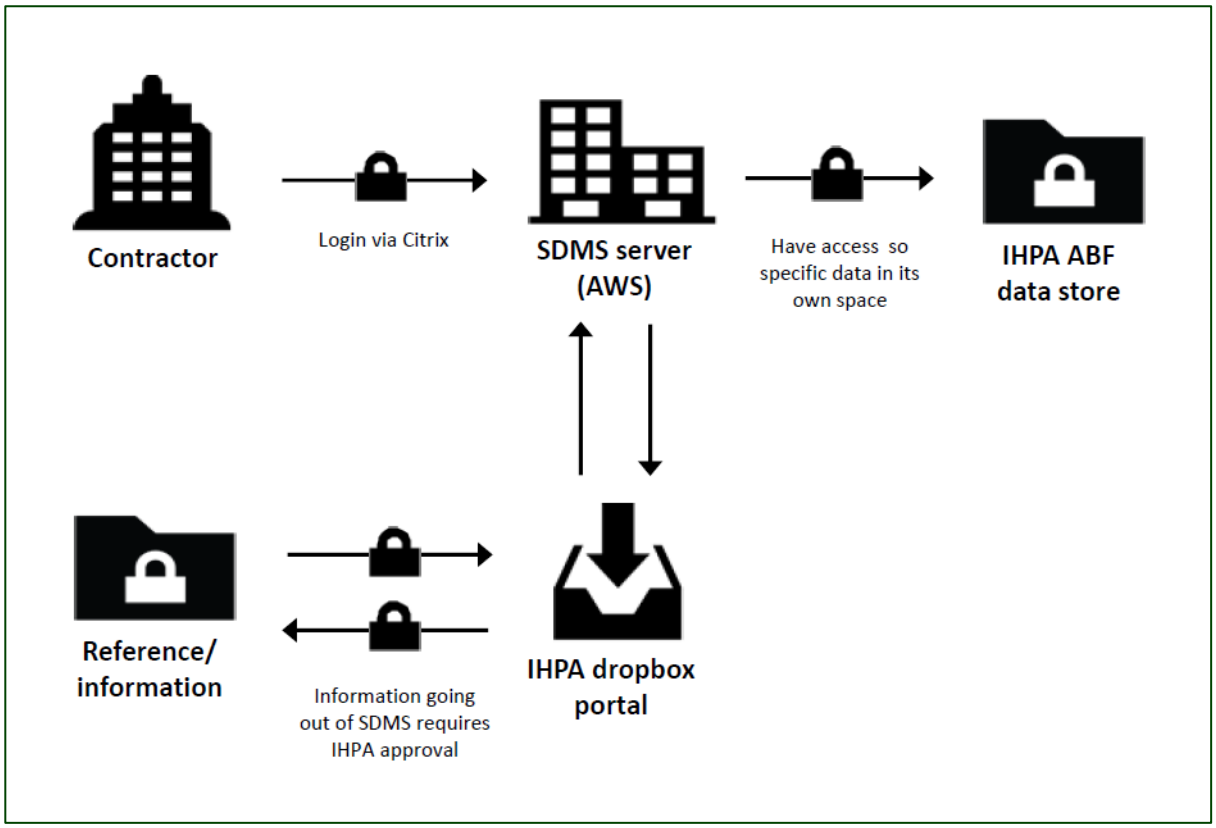

Figure 1. IHPA's Protected Data Access Model. Activity Based Funding data that is collected and stored by IHPA may be accessed securely via the SDMS. The IHPA dropbox portal allows users to securely download data from the SDMS in a number of file formats. IHPA approval is required for all information downloads from the SDMS.

Alternatives to this model require justification plus a risk assessment and must be approved by the CEO of IHPA or 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 solution provide additional restrictions on the storage and transfer of data, as such the transfer of any data to or from the SDMS are only via approval 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 (up to 12 months), or after the granted extended access period.

Any devices supplied by IHPA for the purposes of data access are to be securely returned after being wiped of all data and a Certificate of Destruction to be completed by the requester. IHPA will liaise with the third party to ensure all items are returned via a secure courier.

4.10 Requests for extended access to data

Where the Chair of the Pricing Authority or the CEO of IHPA has approved access to data, the third party may only access this data over a period of 12 months. Where the third party requires access to the data for a longer period than 12 months, a request should be made to the CEO of IHPA. The request should specify 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 data and determine whether extended access to the data is approved.

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 data breach definitions and response procedures are outlined in the Data Breach Response Plan. Upon approval of a data release, IHPA will provide security training along with a copy of the Data Breach Response Plan

Appendix A: IHPA data held

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 Australian Hospital Patient Costing Standards (which outlines how hospital products should be costed) and the Independent Financial Review (which reviews compliance with the 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 patient activity	The Activity Based Funding: Mental health care NBEDS.
Teaching and training activity	The Hospital, teaching and training activities NBEDS. Note that research activities were added to this DSS in 2015-16.

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

Publication
• National Efficient Price Determination • National Efficient Cost Determination • Technical Specifications of the National Pricing Model • National Weighted Activity Unit calculator • Pricing Framework for Australian Public Hospital Services • IHPA Work Program • 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 and Corporate Plan • 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 Impact of New Health Technology Framework

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

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 and positions of other people who will have access to the data within your organisation (please print clearly)

Information request description

Detail the information / dataset requirements, etc.

Time period(s) of interest

Start date: 01/01/2018 End date: 01/01/2018

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.

Linking of data

Do you intend to link the data currently being requested to any other data sources?

Ethics clearance

Please provide evidence of ethics approval, if granted.

Storage, access and disposal of data

Detail where the data will be stored, for what period of time, measures put in place to ensure the security / privacy of the data, who will have access to the data, method and timing of disposal of the data 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
- May only use the confidential information solely 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 ensure that whenever the confidential information is transported or used on a portable device (including USBs and laptops) that the device is encrypted and password protected
- Agree to notify IHPA of the secure disposal of the data on the specified date via a Certificate of Destruction, unless written extension is granted by IHPA
- Agree to cooperate with IHPA in the secure return of portable devices (including USBs and laptops) supplied for the purposes of data supply
- 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	**Date** 01/01/2018

Students, including PhD candidates, must have their research supervisor complete below. **Signature of supervisor**	**Date** 01/01/2018