Australian Government
Australian Institute of Health and Welfare

Governance protocols for National Health Data Hub (NHDH)

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AIHW

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Summary

This document contains the governance protocols agreed for operation of the National Health Data Hub. The governance protocols reflect the ‘current as of date’, either the date of the AIHW Ethics Committee approval or the date that further refinement to processes and procedures are finalised. Approval of changes to the governance protocols will be sought from the AIHW Ethics Committee where the changes are significant and have potential privacy or ethical impacts, and not for minor changes such as refinements to wording or further clarifying processes. Responsibility for determining whether proposed changes to the protocols have ethical or privacy impacts rests with the Unit Head of the AIHW Ethics, Privacy and Legal Unit.

Project approval requirements will reflect the version of the protocols in place at the time of project proposal.

Access to the NHDH will be made available to:

- the AIHW and participant and non-participant jurisdiction(s) represented on the NHDH Advisory Committee.
- Commonwealth, state and territory health portfolio agencies as well as other non-health government departments (and their portfolio agencies)
- External analysts (Australian non-government organisations and analysts attached to Australian universities or private research organisations).

Access to the NHDH will be made available for the following scenarios:

- Standard access for analysis purposes
- Linking additional datasets to NHDH for analysis purposes

1. Introduction

The NHDH is a major national linked health data asset for health research and analysis. It comprises data on admitted patient care services (in public and private hospitals), emergency department services and outpatient services in public hospitals for all participating states and territories. The NHDH also includes Medicare Benefits Schedule (MBS) data; Pharmaceutical Benefits Scheme (PBS) data and Repatriation Pharmaceutical Benefits Scheme (RPBS) data; Residential Aged Care services data; National Death Index (NDI) data and Australian Immunisation Register (AIR) data. A full list of data available in the NHDH is available on the NHDH website.

This document outlines the data governance protocols for the NHDH comprising:

- relevant legislation and oversight
- requirements for host environments
- allowable uses of the linked data asset
- project approval processes
- data asset access and use
- data confidentialisation prior to release from the secure access environment
- outputs and clearance processes
- reports and publications.

As a general rule, principles from the *Five Safes Framework* (for safe people, projects, settings, data and output) are adhered to wherever possible (see Attachment 1 for summary extract of the Five Safes Framework).

2. Overall governance principles

2.1 Legislation and oversight

The principles for overall governance of the NHDH are set out as follows:

- the work will be carried out:
  - within the confidentiality and privacy protections of the *AIHW Act 1987*, the *Privacy Act 1988*, Health Records and Information Privacy Act 2002 No 71 (NSW) and AIHW's existing data governance arrangements (AIHW Data Governance Framework)
  - by authorised users who will sign the AIHW Confidentiality undertaking (Attachment 2)
  - within the secure data linkage arrangements (including separation of identifier and content data) that the AIHW uses as an Accredited Data Service Provider (ADSP).
- all jurisdictions contributing hospitals data to the NHDH, and the AIHW, will contribute to decision-making about the acceptable uses of the NHDH and the ongoing development of governance processes relating to the NHDH, through the NHDH Advisory Committee (see protocols on specific aspects below).

- each participating jurisdiction will have access to its own data and other participating jurisdictions' data in the NHDH. Jurisdictions not contributing data (i.e., non-participants) will also be able to access the NHDH.
- Commonwealth, state and territory health portfolio agencies will have access to the NHDH as will other non-health government departments (and their portfolio agencies).
- external analysts (Australian non-government organisations and analysts attached to Australian universities or private research organisations) will also be able to apply to undertake projects using the NHDH.

2.2 Requirements for host environments

The NHDH has been created by the AIHW in the AIHW Integrating Authority environment. The NHDH, and all its components, is held in the AIHW. Copies of the NHDH will be stored in the AIHW's Research Only Network (RON) and an AIHW managed instance of the ABS' Secure Environment for Access to Data (SEAD). These two host environments satisfy the arrangements outlined below.

Host environments will provide the AIHW Data Custodian with:

- line of sight of all individuals, users and groups with access to the NHDH data
- ability to manage the application and approval process to access the data.
- ability to manage the input (e.g., statistical codes, and all other files, such as metadata files or denominator statistics produced by the ABS or AIHW) and output data with appropriate IT controls to ensure approvals of inbound and outbound files are made by the AIHW Data Custodian e.g., via 'secured gateways'.
- ability to apply customised security and governance arrangements to a specific data collection.

Any host environment will be required to provide the capacity to implement a views management model. At a minimum, this model must ensure that access to data is restricted to analysts with a demonstrated need to use these data and who have received approval and authorisation from the relevant authorities.

The AIHW retains legal responsibility and oversight, and these host environments are recognised as an AIHW environment subject to AIHW protections and obligations under the *AIHW Act 1987* and the *Privacy Act 1988*.

The AIHW remains the data custodian of the NHDH, regardless of the host environment.

The AIHW must ensure that contracted service providers, and any other data hosting entity, as agreed by the NHDH Advisory Committee, are bound by the Australian Privacy Principles and provide the AIHW with the legal ability to exercise its data custodian responsibilities.

Specific aspects of these requirements include:

2.2.1 Secure storage

The secure access environment must incorporate:

- security protocols which are acceptable to the AIHW Data Custodian and AIHW IT Security Advisor
- regular secure backups of data
- sufficient storage and use capacity which will enable efficient data analyses.

- costs which are acceptable to all participants
- strong authentication protocols (such as passwords, security logs, security configurations) adequately secured against unauthorised or inappropriate access, modification, corruption or loss.

2.2.2 Secure use

The secure environment will provide controls under the authority of the AIHW Data Custodian to:

- record physical location of data and who has physical access.
- maintain system and data asset logs and audit trails.
- fix problems with the programs or physical components of the computer relating to data storage as soon as they are known.
- prevent the misuse, interference, loss or unauthorised accessing, modification or disclosure of the data.
- detect and respond to breaches and unauthorised access promptly and appropriately.
- ensure that a mechanism exists whereby outputs from the NHDH can only be removed from the environment after AIHW Data Custodian review and approval.

For the NHDH, the secure environments will also be required to accommodate regular updates and maintenance of the asset. The AIHW will produce and provide the updates of the NHDH, which will be hosted in the secure environments.

2.3 Retention and destruction of data in project workspaces

For the purposes of verification of project findings, files held in project workspaces within NHDH host environments will be securely archived for seven years or as otherwise approved by the AIHW Ethics Committee after the completion of the project. After this period, all files will be destroyed. Access to archived files will require the approval of the NHDH Advisory Committee and will be controlled by the AIHW Data Custodian.

2.4 What the linked data asset can be used for

The NHDH may be used to undertake analyses for health statistical and research purposes. This includes:

1. health research and statistical analyses to inform government health service planning, monitoring and evaluation and health policy development, including official statistics, related insights and reporting.
2. health research and statistical analyses that supports non-government questions about population health and health outcomes. In some instances projects may require a Human Research Ethics Committee (HREC) approval.
3. monitoring variations and patterns of population health outcomes to inform clinical practice review and service delivery for the purposes of ensuring safety and quality of care.
4. performance and health outcomes reporting at a national level.

5. data design and development of performance and productivity measures, subject to agreement before commencement of project. Please note, ongoing official reporting of such measures using the NHDH may not be permitted.

Examples of topics that may be informed by use of the NHDH include:

- population health analysis for cohorts and sub-populations, where approved
- patterns of use and effectiveness of health and residential aged care services, including its interactions with wellbeing characteristics
- health risks for population and particular patient cohorts
- accessibility and effectiveness of services contributing to the management of chronic conditions
- exploring and estimating health system costs associated with procedures, diagnosis, and health events.
- validation of the current treatment pathways for chronic disease management and care
- defining patient/client journeys and assessing efficiency and effectiveness of the health and residential aged care systems
- policies and programs designed to reduce the incidence and severity of disease and injury.

2.5 What the linked data asset cannot be used for

The NHDH cannot be used for purposes that are not under the agreed arrangements for the establishment of the NHDH. Examples of what the NHDH cannot be used for includes, but not limited to:

- purposes not described in the section 'What can the NHDH be used for?'
- to identify and report on any individual
- to identify and report on any service provider or clinical practice, unless approvals from data custodians has been granted
- to identify and report on individual diagnosis of a medical condition(s)
- commercial gain, commercial interest and profit
- official performance monitoring and reporting below the national level including measures from the Australian Health Performance Framework (AHPF), Indigenous Health Performance Framework (IHPF), Report on Government Services (RoGs), National Health Agreement (NHA), unless approvals from data custodians has been granted. Examples include:
    - reporting on the performance of health care and the Australian health system based on performance frameworks at the state and territory level or sub-levels
    - investigating key system performance indicators, such as wait times, at the state and territory level or sub-levels.
- author data insights, findings, and reports at an individual level (e.g. reporting based on the Project-specific Person Numbers (PPNs) or other such row level identifiers)

- administrative and/or compliance reporting purposes, where examples include but not limited to:
    - investigating and reporting the misuse of:
        - health services,
        - health equipment,
        - medical devices,
        - medications dispensed, and
        - biologicals (such as vaccines)
    - reporting on the performance of individuals, clinical practices, or service providers

2.6 Researcher obligations when using the NHDH

Researchers are reminded that data in NHDH are subject to the provisions of section 29 of the Australian Institute of Health and Welfare Act 1987, and as part of signing the Confidentiality Undertaking researchers will not directly or indirectly access, use, divulge, communicate, or retain any information or statistics except as permitted by the Act and in accordance with their project approval conditions.

Projects will not be approved that demonstrates the data in the NHDH will be used for commercial gain. Projects will need to demonstrate how commercial gain will not be awarded as part of the project proposal.

An analyst using the NHDH is not to make a copy of data from the host environment, neither digital nor handwritten, e.g. by a screenshot, screen share or other digital image, or writing down results etc.

2.7 Access to the NHDH

Access to the NHDH will be made available for the following scenarios:

- Standard access for analysis purposes
- Linking additional datasets to NHDH for analysis purposes

Researchers may be granted standard access to the NHDH for analysis purposes for approved projects. Section 2.8 describes the project approval process for standard access.

Please refer to Section 2.9 on how to obtain project approvals for projects requiring additional datasets to be linked to the NHDH.

2.8 Project approvals for standard access to the NHDH

Health research projects within the broad acceptable uses of the NHDH (as outlined in section 2.4) are classed into two broad groups for approval processes.

1. those proposed by government to support government management of the health system (government projects), namely:
    - statistical analysis leading to the production of official statistics, related insights and reporting.

- projects to support government management of the health system such as policy (development and evaluation) and planning.
- public health monitoring, analysis, planning and evaluation.

2. other health research (other health research projects)
    - other health research projects are those within the scope of the agreed purposes for NHDH (see section 2.4) that do not meet the above description for government purposes. These are expected to be initiated largely from the academic and research sectors.

It should be noted that projects for government purposes may involve non-government analysts contributing to the project, where listed on the project proposal.

All standard access projects using the NHDH will not require individual approval by the AIHW Ethics Committee, provided they are assessed in accordance with the project assessment framework described in the NHDH collection approval, EC2023/5/1449. If the project does not align with the pre-approved purposes for use of the NHDH then a separate application to the AIHW Ethics Committee will be required. Additional Human Research Ethics Committee approval will be required for other (non-government led) research projects.

The process to approve projects that use the NHDH have common requirements, regardless of purpose/group. These are described below in the section 2.8.1 on government purposes. There are additional processes required for projects that reflect health research outlined in section 2.8.2.

2.8.1 Government NHDH projects (group 1)

The following outlines the approval of projects for government purposes (group 1):

- project proposals are assessed in accordance with the agreed uses of the NHDH by the AIHW Data Custodian and the AIHW Ethics Committee Delegate (unless the project has received full AIHW Ethics Committee approval). The project description and purpose will need to demonstrate that the project aligns with approved purposes of the NHDH (see section 2.4).
- project proposals need to describe how the project will satisfy the AIHW's requirements for community expectations as detailed in the *AIHW Ethics Committee document Guidance for applicants regarding community expectations*. This consideration can be demonstrated through, for example:
    - consultation with key stakeholders or client group representatives, for example via working groups or advisory groups
    - public engagement such as broad public consultations
    - use of focus groups
    - engagement with expert groups
    - information from engagement events for similar projects
    - government initiatives
    - public polls
    - literature reviews. [1]

[1] https://uksa.statisticsauthority.gov.uk/wp-content/uploads/2019/05/2019_Self-assessment_guidance_V2.1.pdf, p. 15

Plans for managing community expectations, including details of advisory groups and/or consultations, will need to be described in the project proposal (Attachment 3 (government) or Attachment 4 (non-government)).

- for any internal AIHW projects with a First Nations people focus, advice would be sought from the Group Head of the First Nations people Group on potential sensitivities and whether it may also be appropriate to seek external advice from a First Nations people expert, consistent with relevant NHMRC and other relevant guidelines governing ethical aspects of First Nations people projects. For non-AIHW government projects with a First Nations people focus the project leader will need to detail how the project will ensure appropriate consultation and oversight in relation to First Nations people projects. For this purpose, in assessing whether a project has an 'First Nations people focus', regard should be had to 'What is Aboriginal and Torres Strait Islander research?', in (page 6) of the AIATSIS Code of Ethics - for Aboriginal and Torres Strait Islander Research https://aiatsis.gov.au/sites/default/files/2020-10/aiatsis-code-ethics.pdf
- programs of work may be considered as defined by the National Statement under one application.
- project proposals approved by the AIHW following the assessment outlined above, will be circulated to the NHDH Advisory Committee for approval. Projects will be deemed approved if no concerns are raised by the NHDH Advisory Committee within 10 working days of circulation. The exception to this is that projects that include Queensland hospitals data cannot proceed without approval in writing from the Queensland hospitals data custodian.
- projects which do not require hospital data will be sent to the relevant data custodian for approval and provided to the NHDH Advisory Committee for information.
- in addition, projects that include Repatriation Pharmaceutical Benefits Scheme (RPBS) data, with the intention of analysis of the serving defence and DVA client populations, will require Department of Veterans' Affairs (DVA) approval.
- to ensure there is transparency on NHDH analysis projects, the AIHW will maintain a register of projects (using the template Attachment 7) that is published on the NHDH website.
- access to the data asset will be actioned by the AIHW Data Custodian (see Data asset access and use, section 2.7).
- the project leader signs a conditions of use agreement including a retention and document destruction agreement (contained in the project proposal see Attachments 3 and 4).

All analysts will also be required to read the Governance Protocols, attend mandatory training, submit a AIHW Confidentiality Undertaking (Attachment 2) and a AIHW access form to NHDH (Attachment 9).

Approved projects will have NHDH data available via an AIHW Research Only Network (RON) or the managed instance of the Australian Bureau of Statistics (ABS) Secure Environment for Analysing Data (SEAD). The NHDH fee access schedule (Attachment 14) for the SEAD provides the costings for approved projects.

2.8.2 Other health research projects (group 2)

In addition, project proposals for other health research purposes (group 2) (Attachment 4 to be completed) will have additional approval requirements as stipulated in the legislation, or other applicable requirements, of contributing jurisdictions, namely:

- if the project is seeking to include either Australian Capital Territory, South Australia, Victoria, NSW, Queensland, or Tasmania hospitals data they must make a full HREC application for their project with a HREC participating in National Mutual Acceptance (NMA) (link to National Mutual Acceptance Single Ethical Review of Multi-research Ethical projects NMA-Data-Linkage-Guide-March-2023.docx (sharepoint.com)). Once approved by the HREC the project will be considered by the NHDH Advisory Committee. A single HREC approval under the NMA scheme will be mutually recognised across jurisdictions and sufficient to cover the project ethics approval requirement. Through this process, programs of work may be considered as defined by the National Statement under one application.
- if the project is seeking to include RPBS data for analysis specific to the serving defence and DVA client populations, then the Department of Defence and Veterans' Affairs Human Research Ethics Committee (DDVA HREC) approval is required. This HREC approval will be mutually recognised by jurisdictions and sufficient to cover the project approval.
- if the project has a First Nations people focus, then approval from a First Nations people HREC will be required where practical and appropriate, and details of First Nations people engagement and oversight of the project will need to be specified in the project proposal. This HREC approval will be mutually recognised by jurisdictions and sufficient to cover the project approval. For this purpose, in assessing whether a project has an 'First Nations people focus', regard should be had to 'What is Aboriginal and Torres Strait Islander research?', in (page 6) of the AIATSIS Code of Ethics - for Aboriginal and Torres Strait Islander Research https://aiatsis.gov.au/sites/default/files/2020-10/aiatsis-code-ethics.pdf
- if ACT data is accessed, provide the HREC letter of approval, together with the project proposal, to ACT Health to enable a site-specific assessment to be conducted and request a governance approval through ACT Health.
- if Victorian data is being utilised, the HREC must report to the Health Complaints Commissioner in Victoria as per the HPP research exemption guidelines 2.2G.
- access for analysts will only be given to the contributing datasets required for the project. The project proposal will need to specify which datasets are required for the project to enable appropriate access. The NHDH Data Custodian will ensure that the accessible datasets align with those approved for the project by the NHDH Advisory Committee (and Queensland hospitals data custodian where required).

The project leader will need to ensure that any conditions arising from the HREC approval are complied with.

All analysts will also be required to read the Governance Protocols, submit a AIHW Confidentiality Undertaking (Attachment 2) and a AIHW access form to NHDH (Attachment 7).

Approved projects will have NHDH data available via an AIHW managed instance of the Australian Bureau of Statistics (ABS) Secure Environment for Analysing Data (SEAD). The

NHDH fee access schedule (Attachment 14) for the SEAD provides the costings for approved projects.

2.9 Project approvals for linking additional datasets to NHDH

Projects wanting to link non-NHDH datasets to the NHDH will be considered a 'Hub + n' project. In addition to a NHDH Project Proposal, project leaders wishing to make non-NHDH datasets available for use in NHDH will need to complete an application for linkage through the AIHW's Data Integration Services Centre (DISC) and Ethics Committee.

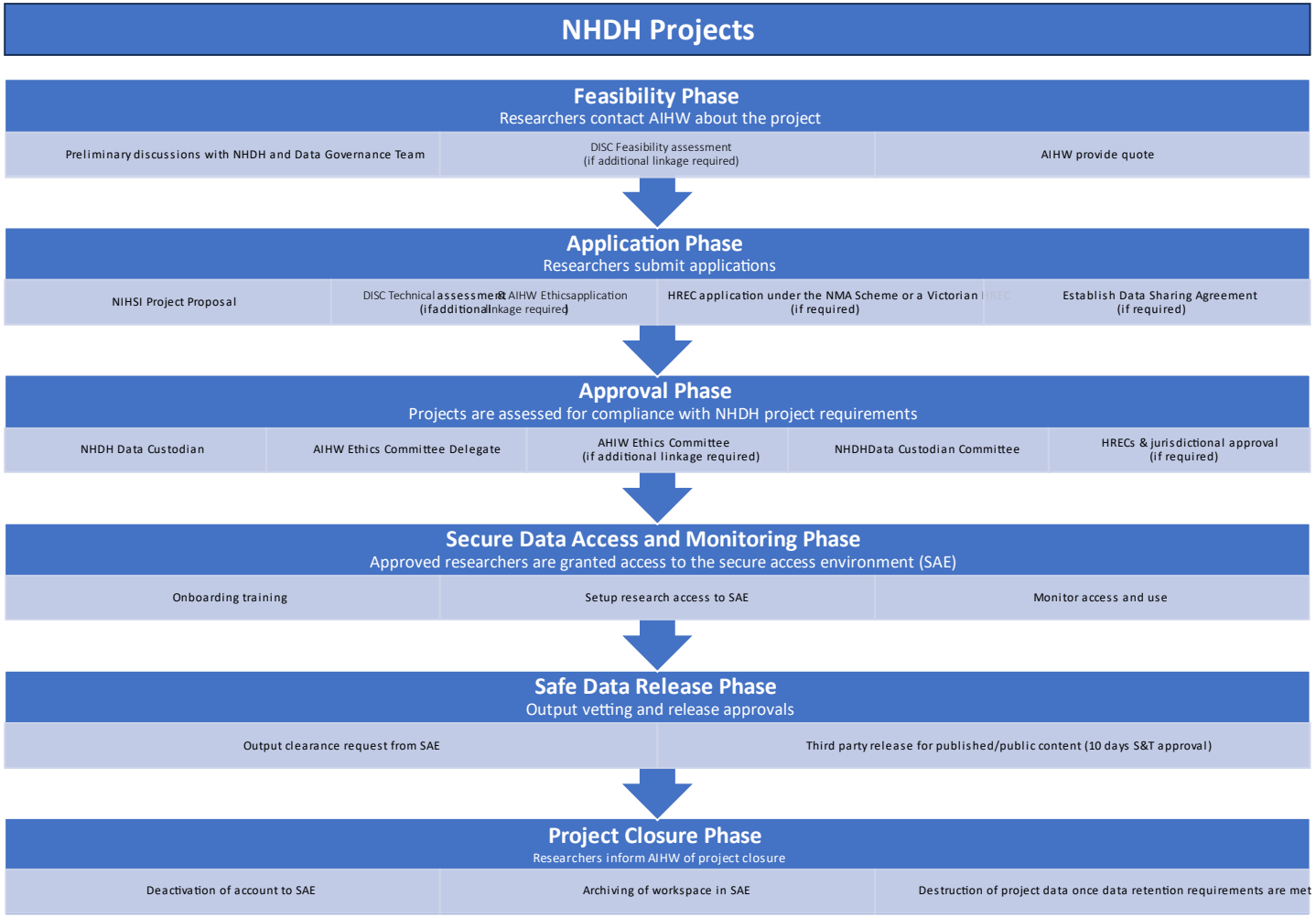
The linkage application involves several steps:

- Feasibility questionnaire (FQ) included in the Hub + n project proposal template (attachment 5 for non-government projects and attachment 6 for government projects)
  The DISC team determines if the linkage is technically feasible and prepares a cost estimate to determine that the linkage is financially feasible. The Ethics Secretariat review the FQ and identify any possible legal issues with the linkage and determine legal feasibility. The NHDH Data Custodian will review the FQ and assess if the proposed use of the data is feasible within the allowed uses of the NHDH.
- Technical assessment and AIHW Ethics Application
  Feasible projects proceed to completing a Technical Assessment (TA) (attachment 15) and an AIHW Ethics application. The TA specifies how the linkage will be conducted and the scope of data involved and forms part of the ethics application. The application through AIHW Ethics Committee will ensure the linkage complies with the Privacy Act 1988, the Australian Privacy Principles (APPs) and the NHMRC National Statement on Ethical Conduct in Human Research 2007 (updated 2018). The AIHW Ethics Committee will be asked to provide a Waiver of Consent or approve any opt-out consent processes as required. Project Leaders will need to have an active AIHW Ethics approval that covers each non-NHDH dataset they wish to link to the NHDH.

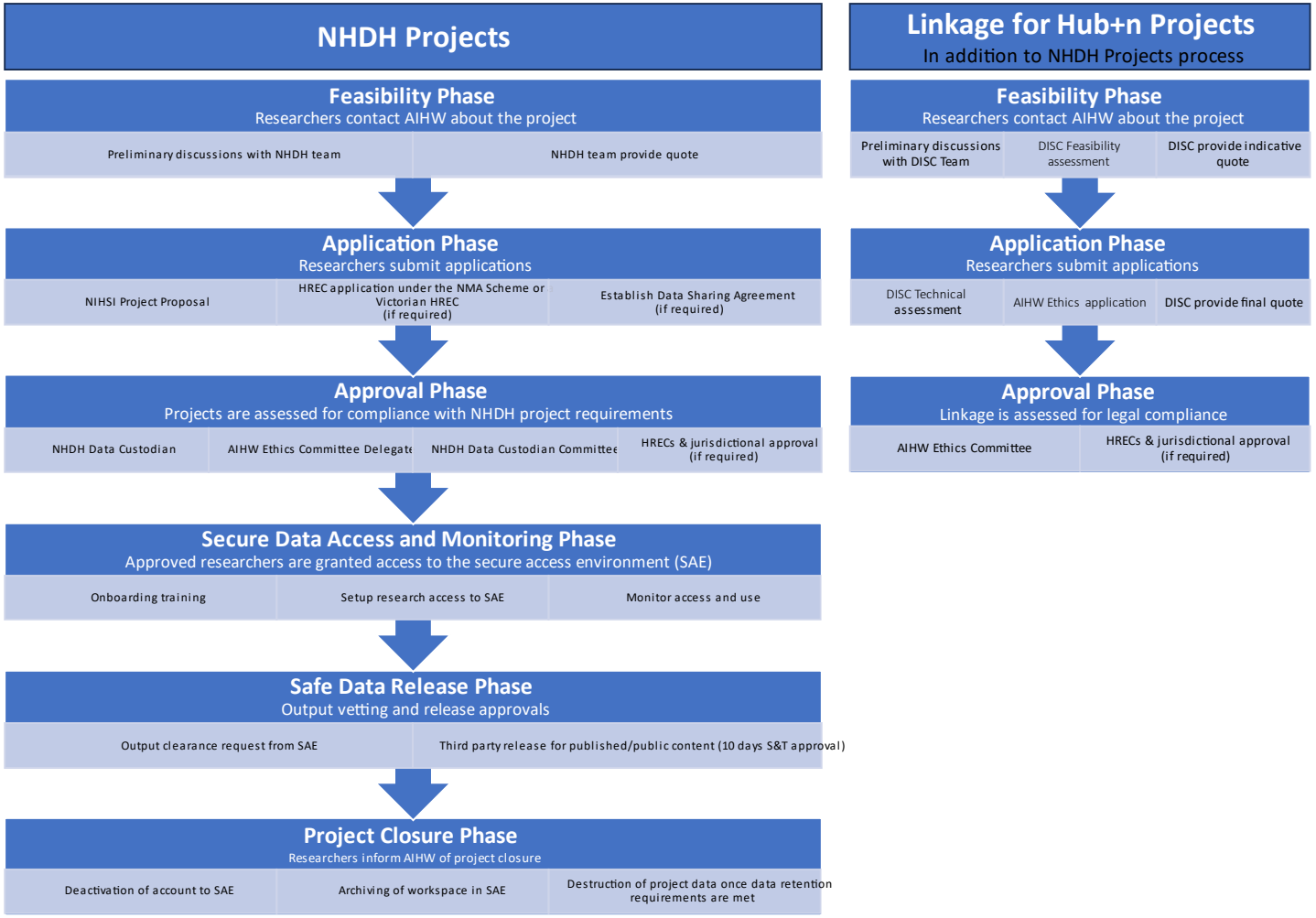
A Hub + n project will also follow the NHDH Governance Protocols processes and approvals for standard access.

Projects involving additional linkage to the NHDH that includes datasets that have less than 100,000 records will need to assign a data manager from the project team who would be responsible for scoping the data and cut the data manually, prior to the broader project team getting access to the scoped data. Such projects that require a comparator group would get access to the NHDH as per Governance Protocols and it would be the responsibility of the data manager to create the comparator group cohort, prior to the broader project team getting access to the comparator group. These services could be delivered by AIHW on a cost recovery basis. Outputs, approvals, and third-party releases would remain unchanged under the Governance Protocols.

NHDH projects approvals process for Standard Access projects



NHDH project approvals process for ‘Hub + n’ projects



2.10 Data access and use

Access to NHDH for approved projects will be provided to participating and non-participating (currently Western Australia and Northern Territory) jurisdiction health departments, health portfolio agencies in all jurisdictions and to other government agencies (Commonwealth, state and territory). Access to these organisations will be via an AIHW managed instance of the ABS' Secure Environment for Analysing Data (SEAD).

Access for non-government analysts will be through the AIHW instance of the SEAD.

Cost will apply to access the NHDH via the SEAD, where applicable, which are described on the NHDH website.

AIHW user access to the NHDH will be through the AIHW Research Only Network (RON). Non AIHW user access to the AIHW RON may be considered on a project-by-project basis and software licence fees will apply.

Access will only be granted for approved projects that demonstrate they align with the approved purposes as outlined in section 2.4. Access in all host environments will be managed by the AIHW Data Custodian and in accordance with the governance arrangements outlined in this protocol. The following data access and use protocols must be adhered to:

- selected staff using the NHDH will be appropriately cleared and authorised by the employing organisation.
- non-government analysts will be granted access based on information provided about their role in undertaking the project and relevant experience. This may be verified with the project leader.
- approved users will be required to sign the AIHW Confidentiality undertaking (Attachment 2) and any relevant jurisdictional confidentiality undertakings which the jurisdictions will provide to the AIHW NHDH Secretariat.
- the NHDH Secretariat will forward the names of those who have signed the Confidentiality undertaking, completed Access forms (Attachment 9), and who have provided details consistent with the NHDH register of analysts (Attachment 7), to the NHDH Data Custodian for approval.
- after all required approvals are received, the AIHW Data Custodian will approve access to users in writing and provide access via the secure access environment administrator, who will implement the approved access permissions.
- AIHW Data Custodian will ensure these names and other details of approved analysts are added to the NHDH register of analysts (Attachment 7).
- in addition to signing the AIHW Confidentiality undertaking and any relevant jurisdictional confidentiality undertakings, conditions or controls, as necessary, will be put in place to prevent someone from seeking to re-identify a person(s) through use of the linked asset (see de-identification protocols below).
- it is the responsibility of the Principal Investigator/Project leader to ensure that all external data custodian and other approvals, including any HREC approvals, if required, are valid for the duration of the project.
- prior to being granted access to the NHDH, all users must attend mandatory onboarding training.

2.11 Data confidentialisation

The following de-identification protocols apply to the data contained in the NHDH:

- the NHDH will not include individual name and address information used to create it. Name and address information will be stored securely and separately from the NHDH content data and only used for data integration purposes as per the Separation principle.
- personal project numbers will be assigned for each individual in lieu of name.
- individual address will be replaced with the Australian Statistical Geography Standard Statistical Area level 2 (SA2) and above.
- all event dates, including date of death, will be replaced with dates in month and year, unless approval is granted to access exact date information.
- the National Health Data and Information Standards Committee (NHDISC) *Guidelines for the Disclosure of Secondary Use Health Information for Statistical Reporting, Research and Analysis (NHDISC Guidelines)* will be complied with.
- the application of additional confidentialisation procedures will be guided by the Office of the Australian Information Commissioner's *De-Identification Decision Making Framework*, to help ensure that de-identified NHDH research datasets no longer contain information about the affairs of an identifiable, or reasonably re-identifiable, person.

2.12 Data outputs

2.12.1 Review and clearance of outputs from NHDH

Confidentialisation of outputs from the NHDH will apply as detailed below:

- unit record data cannot be removed from the host environment.
- an analyst using the NHDH is not to make a copy of data from the host environment, neither digital nor handwritten, e.g. by a screen shot, screen share or other digital image, or writing down results etc.
- project-specific person numbers cannot be removed from the host environment.
- aggregate outputs cannot be taken from the host environment without AIHW Data Custodian approval.
- outputs must comply with the confidentiality and privacy requirements of the *AIHW Act 1987* and the *Privacy Act 1988.* This will be assessed by the AIHW Data Custodian in line with requirements for confidentialisation of aggregate outputs.
- outputs must adhere to the confidentialisation and privacy requirements for the source data i.e., AIHW Hospital Data Collections, MBS, PBS/RPBS, NDI, AIR and residential aged care services data.
- following approval from the AIHW Data Custodian aggregate outputs from the NHDH may be integrated with locally held data (for example, population estimates) for the purposes of report development.
- input and output files must conform to AIHW specifications that may include restrictions on the length of files, the number of files included in a compressed file, and the format of the file.

When seeking clearance of outputs, the analyst will provide the AIHW Data Custodian with a briefing document together with the output (Attachment 12).

The AIHW Data Custodian will maintain a register of outputs removed from the host environment which will be available to the NHDH Advisory Committee (Attachment 11). The register will include the organisation of the analyst, the project that the output is for, a description of the output, and the date of the AIHW Data Custodian approval.

2.12.2 Reports and publications

Review and clearance of reports and publications from the NHDH

NHDH Advisory Committee members will have the role of reviewing and providing comment on reports and publications referred to as a third-party release (Attachment 10). This section also provides guidance on sharing of outputs from the secure environment, prior to them being included in a third-party release. In addition, the DVA will have a role in clearance where the project analyses the defence and veterans' populations through the use of the RPBS data.

All third-party releases will be cleared by the NHDH Data Custodian prior to further circulation. Third party releases can include but not limited to:

- summaries
- draft and final reports
- journal articles and abstracts
- data tables/graphs/plots
- slide deck/PowerPoint presentations

2.12.2.1 Processes for third party release – Group 1a: AIHW projects

NHDH Advisory Committee *approval/advice*

- Where state/territory data is presented in outputs no further distribution can occur until all relevant state/territory approvals have been provided. Outputs are requested to be approved by the NHDH Advisory Committee within 10 working days unless an extension is requested from the NHDH Advisory Committee member. This also includes final reports.
- All other draft outputs will be provided to NHDH Advisory Committee members for information, at the time they are provided for third party release.
- Final reports without state/territory disaggregation will be provided to the NHDH Advisory Committee for information within the embargo period (i.e., prior to publication).

DVA approval/advice

- All NHDH outputs that include analysis of the serving defence and DVA client populations through use of the RPBS data will be provided to the DVA Data Custodian for approval to be provided in writing.

Requirements of the project lead

- Project documentation and draft reports including outputs from the NHDH may be shared with other areas of the AIHW, funders of the project, project steering/advisory committee members and individuals listed as 'Discussants' in the project proposal. Content will be marked draft in confidence, not for further distribution.
- If the full report would contain state/territory data and/or analysis these data are to be redacted from the version shared until state/territory approvals are provided.

- Project documentation and draft reports can be shared with relevant areas of the Department of Health and Ageing or Department of Veterans Affairs for input/critical review, without the need for individuals to be named on the project proposal, however their review should be mentioned in general terms in the project proposal.
- The embargo process at the AIHW will include the NHDH Advisory Committee on the distribution list.
- To provide the NHDH team via NHDH@aihw.gov.au with a link to any published reports, papers or articles based on data from the NHDH.

Steps to follow to seek third party release approval – AIHW users:
1. NHDH aggregate data analysis, checking and request egress from the secure access environment. 2. Third party release product (for example reports, presentations, posters etc) drafted by project team (attached Governance Protocols, section 2.9.2 Reports and publications provides a list of what could be considered for a third-party release) 3. Third party release product can be shared with discussants listed in the project proposal for their review. For example, a draft report can be shared in confidence for review by the Department of Health and Aged Care (DoHAC) or the Department of Veteran Affairs (DVA) as per section 2.12.2.1 of the Governance Protocols. Please note, DoHAC or DVA staff do not need to be listed separately in the NHDH Protocol, however their review should be mentioned in general terms. 4. Project team updates the product based on feedback received. 5. Project team seeks third-party release approval of the product – This approval goes to NHDH Data Custodian and circulated to NHDH Advisory Committee for information unless it contains S&T data (then NHDH Advisory Committee approval is needed) 6. Once approved, the product can be circulated more broadly for feedback if required. 7. Any significant changes to the product following review needs to be approved by the NHDH Data Custodian and circulated to NHDH Advisory Committee for information unless it contains S&T data (then NHDH Advisory Committee approval is needed). Repeat step 5 if required. 8. The AIHW Web and publications team is provided the approved product (final draft) for processing. 9. Embargo: NHDH Advisory Committee members are included in the embargo distribution list. 10. Release: Send link to NHDH team NHDH@aihw.gov.au so the link can be added to the NHDH approved projects webpage. 11. Steps 4, 5, 6 and 7 may have more than one iteration depending on changes made to the third-party release product.

2.12.2.2 Processes for third party release – Group 1b: Non-AIHW government projects

NHDH Advisory Committee *approval/advice*

- Where state/territory data is presented in outputs no further distribution can occur until all relevant state/territory approvals have been provided. Outputs are requested to be approved by the NHDH Advisory Committee within 10 working days unless an

extension is requested from the NHDH Advisory Committee member. This also includes final reports.

- All other draft outputs will be provided to NHDH Advisory Committee members for information, at the time they are provided for third party release.
- Final reports without state/territory disaggregation will be provided to the NHDH Advisory Committee for information within the embargo period (i.e., prior to publication).

DVA approval/advice

- All NHDH outputs that include analysis of the serving defence and DVA client populations through use of the RPBS data will be provided to the DVA Data Custodian for approval to be provided in writing.

Requirements of the project lead

- Project documentation and draft reports including outputs from the NHDH may be shared within the government organisation, project steering/advisory committee members and individuals listed as 'Discussants' in the project. Content will be marked draft in confidence, not for further distribution.
- If the full report would contain state/territory data and/or analysis these data are to be redacted from the version shared until state/territory approvals are provided[2].
- To provide the NHDH team via NHDH@aihw.gov.au with a link to any published reports, papers or articles based on data from the NHDH.

Steps to follow to seek third party release approval – non-AIHW Government users:

1. NHDH Data analysis, checking and egress.
2. Third party release drafted by project team (section 2.9.2 Reports and publications provides a list of what could be considered a third-party release)
3. Internal discussants listed in project proposal – draft report can be shared in confidence for review.
4. Review and third-party release approval of NHDH publication/report – by NHDH Data Custodian and circulated to NHDH Advisory Committee for information unless it contains S&T data (then NHDH Advisory Committee approval is needed)
5. External (Department of Health and Aged Care, Advisory Committees, Working Groups) reviews are conducted following third-party release approval.
6. Any significant changes need to be approved by the NHDH Data Custodian and circulated to NHDH Advisory Committee for information unless it contains S&T data (then NHDH Advisory Committee approval is needed)
7. Embargo: NHDH Advisory Committee members are included in embargo list
8. Release: Send link to NHDH team NHDH@aihw.gov.au so the link can be added to the NHDH approved projects webpage.

Steps 3,4,5 and 6 may have more than one iteration depending on changes made to the third-party release.

[2] A PDF with state/territory content black highlighted or a word document with all state/territory content removed. Header table and placeholders are acceptable.

2.12.2.3 Processes for third party release – Group 2: Non-government projects

NHDH Advisory Committee *approval*

- All NHDH outputs will be provided to the NHDH Advisory Committee for approval prior to further distribution of the content. Outputs that contain state/territory disaggregation will require approval in writing. Other outputs will be deemed approved after 10 working data unless an extension is requested from the NHDH Advisory Committee member.

DVA approval/advice

- All NHDH outputs that include analysis of the serving defence and DVA client populations through use of the RPBS data will be provided to the DVA Data Custodian for approval to be provided in writing. Approval will be requested within 10 working days.

Requirements of the project lead/who content can be shared with

- All draft content for the third-party release is to be marked draft in confidence.
- Must list all individuals or organisations who will be engaged and may have access to project outputs during the investigation phase of the project as aligned with the project proposal analyst template (Attachment 4). Content can only be provided to those named in the project proposal.
- All final reports/outputs will need to allow an embargo period for the NHDH Advisory Committee to review prior to submission for publication. This period will be no less than 10 working days but may be longer (no longer than 30 working days) if stipulated by a jurisdiction's approval of the project.
- To provide the NHDH team via NHDH@aihw.gov.au with a link to any published reports, papers or articles based on data from the NHDH.

2.12.2.4 Other general principles

In addition, the following principles apply:

- joint jurisdictional reports may be shared in-confidence between other jurisdictions participating in the project for the purposes of methods and report development prior to provision to full NHDH Advisory Committee for approval.
- reports that include outputs relating to individual jurisdictions* cannot be published or provided to a third party (or an organisation) without the written approval of those jurisdictions. This includes circulation to:
  - the National Cabinet
  - other government and non-government bodies
  - release into the public domain (e.g., in the form of publications or conference presentations).
- for release of reports/outputs into the public domain, the current embargo arrangements used for report release within each participating and non-participating jurisdiction will apply, with reports circulated to each of these jurisdictions.
- any report/output or publication needs to acknowledge:
  - the jurisdiction(s) whose data are used.
  - the AIHW as Data Custodian and creator of the NHDH

  - the contributions of the NHDH Advisory Committee members in providing advice on those publications and presentations
  - any involvement contributing jurisdictions have had through established engagement forums.
- While there is general Ethics Committee approval for the NHDH and its use, participants should consult with journals on the matter of ethics requirements before undertaking to publish and should seek approval via their local Human Research Ethics Committee (HREC) if required.

* The Commonwealth Department of Health and Aged Care has indicated that it does not need to approve reports and publications generated from the NHDH, noting that AIHW will seek approval for reports and publications commissioned by the Department through separate arrangements, and the above embargo arrangements for release of reports in the public domain. Reports and publications will still be provided to the Commonwealth at the same time as being circulated to other NHDH Advisory Committee members, so that the Commonwealth has the option to provide feedback.

3. Glossary

Glossary

NHDH	AIHW National Health Data Hub (NHDH) repository which contains hospital services data, Medicare Benefits Schedule, (MBS) and Pharmaceutical Benefits Scheme (PBS) data, Residential Aged Care Services data and National Death Index (NDI) data.
Host environment	Secure ICT environment(s) where the NHDH will be stored and accessed by approved participants.
Data Custodian	Data Custodian is an AIHW staff member with delegation from the AIHW Chief Executive Officer to exercise overall responsibilities for a specified data collection in accordance with legislation, the AIHW's governance instruments and any specific conditions for use applicable to that data collection.
Section 29 of the AIHW Act 1987	https://www.legislation.gov.au/Series/C2004A03450
Data	For the purposes of the NHDH, data will be defined as unit record data held within the NHDH.
Outputs	For the purposes of the NHDH, outputs will be defined as any aggregate statistics derived from the data contained in the NHDH.
Reports	For the purposes of the NHDH, a report is any product for publication or other dissemination to third parties that incorporates outputs from the NHDH. Reports may include written material, findings and comments about the outputs developed using the NHDH.
Third party	An individual or organisation external to the participant and non-participant jurisdictions as represented on the NHDH Advisory Committee, and the AIHW.
Participants	The following data providers are participants in the NHDH: Commonwealth Department of Health (the Department), Australian Institute of Health and Welfare (AIHW), and those state and territory health authorities that have provided patient identifiers to enable the inclusion of their hospital data in the NHDH.
Non-participants	State and territory health authorities that have NOT provided patient identifiers to enable the inclusion of their hospital data in the NHDH.
Individual	A person or organisation

Jurisdiction	A state and territory (as represented by their respective health authorities) and the Australian Government (as represented by the Department).
De-identified	De-identification involves two steps. The first is the removal of direct identifiers from a dataset. The second is taking one or both of the following additional steps: • the removal or alteration of other information that could potentially be used to re-identify an individual • the use of controls and safeguards in the data access environment to prevent re-identification.
Confidentialisation	The process of removing identifiers and assessing and managing the risk of indirect identification occurring in the data.
Re-identification	Any action, such as the linkage or addition of information to a de-identified dataset, which allows the identification of individuals.
External Analyst	Includes staff and contractors from non-government organisations, or individuals.
Government Analyst	Is the analyst employed or contracted to a commonwealth or state/territory government agency?

Attachments:

Attachment 1: Extract from *"Five Safes: designing data access for research"*

Attachment 2: AIHW Confidentiality undertaking

Attachment 3: NHDH Project proposal and conditions of use – government project template

Attachment 4: NHDH project proposal and conditions of use – non-government health research project template

Attachment 5: NHDH project proposal and conditions of use – non-government health Hub+n research project template

Attachment 6: HUB+n project proposal and conditions of use template – government project

Attachment 7: Register of NHDH projects

Attachment 8: Register of NHDH analysts

Attachment 9: Analyst Access forms to NHDH

Attachment 10: NHDH third party release template

Attachment 11: Register of NHDH outputs

Attachment 12: Output clearance request briefing template.

Attachment 13: Input clearance request briefing template.

Attachment 14: Costings for access to the NHDH

Attachment 15: Technical Assessment (Hub+n)

Attachment 16: NHDH project amendments

Attachment 1: Extract from *Five Safes Framework*

Safe projects (i.e., use)

Is this use of the data appropriate?

Safe people

Can the Analyst be trusted to use it in an appropriate manner?

Safe data

Is there a disclosure risk in the data itself?

Safe settings

Does the access facility limit unauthorised use?

Safe output

Are the statistical results non-disclosure?

Reference:

Desai T; Ritchie F Welpton R 2016. Five Safes: designing data access for research. Economics Working Paper Series 1601. Bristol: University of the West of England.

Attachment 2: AIHW Confidentiality undertaking

Confidentiality undertaking –
staff, contractors and consultants

Instructions

This agreement is designed to be completed electronically and then printed and authorised by the appropriate Unit Head or Delegate. Complete the form by entering the information in the fields provided.

1. All staff members, contractors, consultants (including those paid through a recruitment agency), Working group/Advisory group members and any other person being authorised to access AIHW ICT systems and/or approved aggregate output released from AIHW secure access environments (prior to third party release approval) must read and sign this agreement.

Details	
Name (**uppercase**):	
Company / Agency name – if applicable (**uppercase**):	

- I understand that the Australian Institute of Health and Welfare acquires and holds health- and welfare- related information which is 'information concerning a person' and which is subject to the provisions of section 29 of the *Australian Institute of Health and Welfare Act 1987* (Attachment A).
- I understand that I may become an 'informed person' within the meaning of section 29 of the Act and that criminal penalties, including imprisonment, apply for improperly divulging or communicating information to which section 29 applies.
- I undertake that I will not directly or indirectly access, use, divulge, communicate or retain any information or statistics except as permitted by the Act and in accordance with my role.
- I understand that the Institute acquires and holds 'personal information' as defined in Section 6(1) of the *Privacy Act 1988* (Cth).
- I understand that personal information must be managed in accordance with the: Australian Privacy Principles in Schedule 1 of the Privacy Act, and associated guidelines and regulations, for example the *Guidelines under section 95 of the Privacy Act 1988,* and

I agree to protect the confidentiality of personal information in accordance with these Acts and Guidelines.

Executed as a Deed by:		
Signature:		Date: / /
Authorised and witnessed by:		
Name in full (**uppercase**):		
Signature:		Date: / /

Attachments

A. Confidentiality - an extract from section 29 of the *Australian Institute of Health and Welfare Act 1987*.

B. Australian Privacy Principles in the *Privacy Act 1988* Schedule 1 **[print latest version and hand to signatory]**

C. *Guidelines under section 95 of the Privacy Act 1988* (NHMRC, 2014) https://www.nhmrc.gov.au/about-us/publications/guidelines-under-section-95-privacy-act-1988 **[print latest version and hand to signatory]**

ICT Servicedesk use only:	
Date received:	/ /
Name of actioner:	Date: / /

Attachment A: Section 29 of the *Australian Institute of Health and Welfare Act 1987*

(i) 29 Confidentiality

(1) Subject to this section, a person (in this subsection called the ***informed person***) who has:

(a) any information concerning another person (which person is in this section called an ***information subject***), being information acquired by the informed person because of:

(i) holding an office, engagement or appointment, or being employed, under this Act.

(ii) performing a duty or function, or exercising a power, under or in connection with this Act; or

(iii) doing any act or thing under an agreement or arrangement entered into by the Institute; or

(b) any document relating to another person (which person is in this section also called an ***information subject***), being a document furnished for the purposes of this Act.

shall not, except for the purposes of this Act, either directly or indirectly:

(c) make a record of any of that information or divulge or communicate any of that information to any person (including an information subject).

(d) produce that document to any person (including an information subject); or

(e) be required to divulge or communicate any of that information to a court or to produce that document in a court.

Penalty: $2,000 or imprisonment for 12 months, or both.

(2) Subject to subsections (2A) and (2B), nothing in this section prohibits:

(a) a person from divulging or communicating information, or producing a document, to the Minister if it does not identify an information subject.

(b) a person from divulging or communicating information, or producing a document, to a person specified in writing by the person (in this subsection called the ***information provider***) who divulged or communicated the information, or produced the document, directly to the Institute.

(c) a person from divulging or communicating information, or producing a document, to a person specified in writing by the Ethics Committee if to do so is not contrary to the written terms and conditions (if any) upon which the information provider divulged or communicated the information, or produced the document, directly to the Institute; or

(d) the publication of conclusions based on statistics derived from, or of particulars of procedures used in, the work of the Institute, if:

(i) to do so is not contrary to the written terms and conditions (if any) upon which an information provider divulged or communicated information relevant to the publication, or produced a document relevant to the publication, directly to the Institute; and

(ii) the publication does not identify the information subject.

(2A) Paragraph (2)(c) applies only to information that is health-related or welfare-related information and statistics.

(2B) Paragraph (2)(c) applies to a document only to the extent to which the document contains health-related or welfare-related information and statistics.

(3) A person to whom information is divulged or communicated, or a document is produced, under paragraph (2)(a), (b) or (c), and any person under the control of that person is, in respect of that information or document, subject to subsection (1) as if the person were a person exercising powers, or performing duties or functions, under this Act and had acquired the information or document in the exercise of those powers or the performance of those duties or functions.

(4) In this section:

(a) ***court*** includes any tribunal, authority or person having power to require the production of documents or the answering of questions.

(b) ***person*** includes a body or association of persons, whether incorporated or not, and also includes:

(i) in the case of an information provider—a body politic; or

(ii) in the case of an information subject—a deceased person.

(c) ***produce*** includes permit access to.

(d) ***publication***, in relation to conclusions, statistics or particulars, includes:

(ii) the divulging or communication to a court of the conclusions, statistics or particulars; and

(iii) the production to a court of a document containing the conclusions, statistics or particulars; and

(e) a reference to information concerning a person includes:

(i) a reference to information as to the whereabouts, existence or non-existence of a document concerning a person; and

(ii) a reference to information identifying a person or body providing information concerning a person.

Attachment 3: NHDH project proposal and conditions of use template – government project

Please keep the project proposal brief and delete instructions in blue when complete.

Refer to the National Health Data Hub (NHDH)) *Governance protocols* for detailed information about the operation of the NHDH.

Project identifier

Assigned by the NHDH secretariat.

Project title

Auspicing body

If applicable, e.g., the Department of Health

Organisation nominating the project.

E.g., NSW, Vic, Qld etc.

Project leader

Include name, organisation, email address and phone number.

Project analysts and discussants

If applicable, please list other people or organisations (e.g., consultants) who will have access to project outputs and will discuss project outputs during the investigation phase of the project. These people will need to sign a s29 Confidentiality Undertaking (Attachment 2). It is the responsibility of the project leader to ensure the s29 Confidentiality Undertaking are signed. The AIHW has embedded the *five safes framework* into our approach in making decisions about sharing and releasing data. Researchers will have the knowledge, skills and incentives to act in accordance with required standards of behaviour under the five safes framework.

Include name, organisation, email address.

Project advisors and other contributors

If applicable, please list other advisors or other contributors to the project. This may include peer review groups, committees, and external advisors These people will need to sign a s29 Confidentiality Undertaking (Attachment 2). It is the responsibility of the project leader to ensure the s29 Confidentiality Undertaking are signed.

Include name, Committee or group.

Project objective

What are the main objectives of the project? Please refer to the *Governance protocols* for intended uses of the NHDH.

Please state whether Queensland hospitals data will be required for the project.

Project Methodology

What are the methodology approaches you plan to use in your projects? e.g how will cohorts be defined or outcomes be determined?

Default datasets or by exception datasets.

The NHDH data design uses ***default* data modules** and ***by exception* data modules.** The *by exception* data modules are characterised by containing the more sensitive data items such as exact/full dates for admission, separation, departure, presentation, referral, prescription, and service dates. Please note, the *default* data modules contain month and year of most dates but not the day of the date.

By exception data modules have been created for:

- All hospital content data modules
- MBS, PBS and NDI content data modules
- RAC and HCP aged care content data modules

Do you require access to by exception datasets.

No

Yes

If you have ticked yes. Please provide justification for access to the by exception data modules.

Collections used in the Project

Data modules	**Planned to be included in Analysis Yes/No**	**Are you requesting access to by exception data modules?** **Yes/No**
Patient Demographics: PATIENTS_DEMOGRAPHY	Yes (all researchers have access to this)	NA

ABS Country Classification Codes for Birth Country: SACC_CODES	Yes (all researchers have access to this)	NA
National Death data modules		
National Death Index: NDI_CONTENT		
Aged Care data modules		
Residential Age Care		N/A
Home Care		N/A
Home Support		N/A
Flexible Care		N/A
Aged Care Eligibility Assessment		N/A
Australian Immunisation Register data modules		
Child data modules: **Natural Immunity Details** (**Child**): AIR_CONTENT_NTRL_IMMNTY **Medicare Contraindication Vaccines details (child):** AIR_CONTENT_CNTRNDCTN **Vaccination Episodes that Individuals Received (Child)**: AIR_CONTENT_VACCNTN_EPSD		
Adult data modules: **Natural Immunity Details (Adult):** AIR_CONTENT_NTRL_IMMNTY **Medicare Contraindication Vaccines details (Adult):** AIR_CONTENT_CNTRNDCTN **Vaccination Episodes that Individuals Received (Adult):** AIR_CONTENT_VACCNTN_EPSD		
Vaccination Supply Details: AIR_DM_SUPPLR_VCCNE	Yes (all users have access to this when requesting AIR modules)	N/A
Antigen Codes and Vaccine Codes: AIR_DM_ANTGN_VCCNE_MP	Yes (all users have access to this when requesting AIR modules)	N/A

File Extract Information: AIR_CONTENT_PERSON_CURRENT	Yes (all users have access to this when requesting AIR modules)	N/A
COVID-19 Vaccination data: AIR_DM_CVD_CMPLNCE_STTS	Yes (all users have access to this when requesting AIR modules)	N/A
Antigen Codes and Antigen Names: AIR_DM_ANTGN	Yes (all users have access to this when requesting AIR modules)	N/A
Medicare Benefits Schedule		
Medicare Benefits Schedule (MBS): MBS_CONTENT		
Supplementary Data Speciality Codes: MBS_REG_SPECIALTY_CODES	Yes (all users have access to this when requesting MBS modules)	N/A
Map of MBS Item Descriptions: MBS_ITEM_MAP	Yes (all users have access to this when requesting MBS modules)	N/A
Pharmaceutical Benefits Scheme		
Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS): PBS_CONTENT		
Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS) - Map of PBS Item Code Descriptions: PBS_ITEM_MAP	Yes (all users have access to this when requesting PBS)	N/A
Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS) - Supplementary Data Speciality Codes: PBS_DERIVED_MAJOR_SPECIALITY	Yes (all users have access to this when requesting PBS)	N/A

Will you be using Repatriation Pharmaceutical Benefits Scheme (RPBS) specifically to analyse the veteran/defence population use of pharmaceuticals Please state: Yes, No

Hospital Data		
Hospital Data: HOSPITAL_CONTENT_DATA (Public hospital establishment information)	Yes (all users have access to this when requesting hospitals data listed below)	N/A

If the intention is to use all available states/territories then indicate in last row, otherwise place an X for each combination of hospitals collection and state/territory.

State/Territory	**Admitted Patient Care data** (AP_CONTENT)	**Non-Admitted Patient data** (NAP_CONTENT)	**Emergency Department Care data** (ED_CONTENT)	**Are you requesting access to *by exception* hospital data modules?** Yes/No
NSW				
Vic				
Qld				
SA				
Tas				
ACT				
All available				

Project duration, and retention and destruction of data

Planned completion date.

DD/MM/YY

Archiving and Retention of data

As determined by section 2.3 of the Governance Protocols, files will be archived for seven years after the completion of the project unless a Human Research Ethics Approval (HREC) provides another period. Please provide the HREC period if different from section 2.4 of the protocols.

Consideration of community expectations

Please include details of how community expectations around the project are being considered including plans and purpose for consultation with appropriate groups.

Non-exhaustive list of examples

- Consultation with key stakeholders or client group representatives, for example via working groups or advisory groups
- public engagement such as broad public consultations
- use of focus groups
- engagement with expert groups
- information from engagement events for similar projects
- government initiatives
- public polls
- literature reviews. [1]

Projects with a First Nations people focus.

For any internal AIHW research with a First Nations people focus, advice would be sought from the Group Head of the First Nations people Group on potential sensitivities and whether it may also be appropriate to seek external advice from a First Nations people *expert.*

Please outline planned consultations with advisors who can support the appropriate and sensitive reporting of data.

[1] https://uksa.statisticsauthority.gov.uk/wp-content/uploads/2019/05/2019_Self-assessment_guidance_V2.1.pdf, p. 15

Outputs and reports

Please provide information on:

- whether jurisdictions will be identified in the outputs and reports
    - please specify jurisdictions and parent data collections being presented.
- whether individual entities (e.g., hospitals) will be identified in outputs and reports.
- whether comparisons of First Nations people and non-Indigenous people/other Australians/all Australians will be made in the outputs and reports
- whether outputs and reports will be distributed to third parties or published
- the audience for the outputs and reports
- where reports are to be published, the name of the publication.
- timeframes for the release of reports.

Commercial Gain

Please provide information on whether this project could be used for commercial gain.

Disclosure agreement

A description of your project may be included on the AIHW website.

Is there a non-discloser agreement on this project?

Yes	No
☐	☐

Project Leader

Name **Signature**	**Date**

AIHW Head of Ethics, Privacy and Legal Unit

I support the project noting the following, **Name** **Signature**	**Date**

NHDH Data Custodian

I support the project noting the following, **Name** **Signature**	**Date**

NHDH Advisory Committee member

Approved	☐	
Approved with conditions (please specify)	☐	
Not approved	☐	
Name		
Signature		**Date**

Attachment 4: NHDH project proposal and conditions of use template – health research project

non-government organisations and analysts attached to universities or private research organisations.

Please keep the project proposal brief and delete instructions in blue when complete.

Refer to the National Health Data Hub (NHDH) *Governance protocols* for detailed information about the operation of the NHDH.

Project identifier

Assigned by the NHDH secretariat.

Project title

Auspicing/Funding body

If applicable, e.g., The Department of Health etc.

Organisation nominating the project.

E.g., NSW, Vic, Qld, University etc.

Project leader

Include name, organisation, email address and phone number, and brief summary of experience/credentials.

Project Analysts

List intended analysts working on the project. Include name, organisation, email address and phone number, and brief summary of experience/credentials. These are people who will require access to the secure environment in addition to the project leader.

The AIHW has embedded the *five safes framework* into our approach in making decisions about sharing and releasing data. Researchers will have the knowledge, skills and incentives to act in accordance with required standards of behaviour under the five safes framework.

Project analysts and discussants

If applicable, please list other people or organisations (e.g., consultants) who will have access to project outputs and will discuss project outputs during the investigation phase of the project. These people will need to sign a s29 Confidentiality Undertaking (Attachment 2). It is the responsibility of the project leader to ensure the s29 Confidentiality Undertaking are signed.

Include name, organisation, email address.

Project advisors and other contributors

If applicable, please list other advisors or other contributors to the project. This may include peer review groups, committees, and external advisors These people will need to sign a s29 Confidentiality Undertaking (Attachment 2). It is the responsibility of the project leader to ensure the s29 Confidentiality Undertaking are signed.

Include name, Committee or group.

Project objective

What are the main objectives of the project? Please refer to the *Governance protocols* for intended uses of the NHDH.

Please indicate which states/territories hospitals data will be required for the project.

Project Methodology

What are the methodology approaches you plan to use in your projects? e.g how will cohorts be defined or outcomes be determined?

Default datasets or by exception datasets.

The NHDH data design uses ***default* data modules** and ***by exception* data modules.** The *by exception* data modules are characterised by containing the more sensitive data items such as exact/full dates for admission, separation, departure, presentation, referral, prescription, and service dates. Please note, the *default* data modules contain month and year of most dates but not the day of the date.

By exception data modules have been created for:

- All hospital content data modules
- MBS, PBS and NDI content data modules
- RAC and HCP aged care content data modules

Do you require access to by exception datasets.

No ☐

Yes ☐

If you have ticked yes. Please provide justification for access to the by exception data modules.

Collections used in the Project

Data modules	Planned to be included in Analysis Yes/No	Are you requesting access to by exception data modules? Yes/No
Patient Demographics: PATIENTS_DEMOGRAPHY	Yes (all researchers have access to this)	NA
ABS Country Classification Codes for Birth Country: SACC_CODES	Yes (all researchers have access to this)	NA
National Death data modules		
National Death Index: NDI_CONTENT		
Aged Care data modules		
Residential Age Care		N/A
Home Care		N/A
Home Support		N/A
Flexible Care		N/A
Aged Care Eligibility Assessment		N/A
Australian Immunisation Register data modules		
Child data modules: **Natural Immunity Details (Child):** AIR_CONTENT_NTRL_IMMNTY **Medicare Contraindication Vaccines details (child):** AIR_CONTENT_CNTRNDCTN **Vaccination Episodes that Individuals Received (Child)**: AIR_CONTENT_VACCNTN_EPSD		
Adult data modules: **Natural Immunity Details (Adult):** AIR_CONTENT_NTRL_IMMNTY **Medicare Contraindication Vaccines details (Adult):** AIR_CONTENT_CNTRNDCTN		

Vaccination Episodes that Individuals Received (Adult): AIR_CONTENT_VACCNTN_EPSD		
Vaccination Supply Details: AIR_DM_SUPPLR_VCCNE	Yes (all users have access to this when requesting AIR modules)	N/A
Antigen Codes and Vaccine Codes: AIR_DM_ANTGN_VCCNE_MP	Yes (all users have access to this when requesting AIR modules)	N/A
File Extract Information: AIR_CONTENT_PERSON_CURRENT	Yes (all users have access to this when requesting AIR modules)	N/A
COVID-19 Vaccination data: AIR_DM_CVD_CMPLNCE_STTS	Yes (all users have access to this when requesting AIR modules)	N/A
Antigen Codes and Antigen Names: AIR_DM_ANTGN	Yes (all users have access to this when requesting AIR modules)	N/A
Medicare Benefits Schedule		
Medicare Benefits Schedule (MBS): MBS_CONTENT		
Supplementary Data Speciality Codes: MBS_REG_SPECIALTY_CODES	Yes (all users have access to this when requesting MBS modules)	N/A
Map of MBS Item Descriptions: MBS_ITEM_MAP	Yes (all users have access to this when requesting MBS modules)	N/A
Pharmaceutical Benefits Scheme		

Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS): PBS_CONTENT		
Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS) - Map of PBS Item Code Descriptions: PBS_ITEM_MAP	Yes (all users have access to this when requesting PBS)	N/A
Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS) - Supplementary Data Speciality Codes: PBS_DERIVED_MAJOR_SPECIALITY	Yes (all users have access to this when requesting PBS)	N/A
Will you be using Repatriation Pharmaceutical Benefits Scheme (RPBS) specifically to analyse the veteran/defence population use of pharmaceuticals Please state: Yes, No		
Hospital Data		
Hospital Data: HOSPITAL_CONTENT_DATA (Public hospital establishment information)	Yes (all users have access to this when requesting hospitals data listed below)	N/A

If the intention is to use all available states/territories then indicate in last row, otherwise place an X for each combination of hospitals collection and state/territory.

State/Territory	**Admitted Patient Care data** (AP_CONTENT)	**Non-Admitted Patient data** (NAP_CONTENT)	**Emergency Department Care data** (ED_CONTENT)	**Are you requesting access to *by exception* hospital data modules?** Yes/No
NSW				
Vic				
Qld				
SA				
Tas				

ACT				
All available				

Project duration, and retention and destruction of data

Planned completion date.

DD/MM/YY

Archiving and Retention of data

As determined by section 2.3 of the Governance Protocols, files will be archived for seven years after the completion of the project unless a Human Research Ethics Approval (HREC) provides another period. Please provide the HREC period if different from section 2.4 of the protocols.

Consideration of community expectations

Please include details of how community expectations around the project are being considered including plans and purpose for consultation with appropriate groups.

- non-exhaustive list of examples Consultation with key stakeholders or client group representatives, for example via working groups or advisory groups
- public engagement such as broad public consultations
- use of focus groups
- engagement with expert groups
- information from engagement events for similar projects
- government initiatives
- public polls
- literature reviews. [1]

Projects with a First Nations people focus.

Will the project have a focus of analysis on the First Nations people population?

Yes No

Project proposals should address how external advice from First Nations people expert is being sought and how appropriate consultation and oversight is provided during the life of the project.

Non-government research proposals where First Nations people are a focus must obtain.

First Nations people Human Research Ethics Committee approval (HREC). For guidance in planning, designing, and conducting such research, please consult the NHMRC *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities:*

[1] https://uksa.statisticsauthority.gov.uk/wp-content/uploads/2019/05/2019_Self-assessment_guidance_V2.1.pdf, p. 15

Guidelines for researchers and stakeholders 2018, as well as the guidance provided by the First Nations people HRECs.

Outputs and reports

Please provide information on:

- whether jurisdictions will be identified in the outputs and reports
    - please specify jurisdictions and parent data collections being presented.
- whether individual entities (e.g., hospitals) will be identified in outputs and reports.
- whether comparisons of First Nations people and non-Indigenous people/other Australians/all Australians will be made in the outputs and reports
- whether outputs and reports will be distributed to third parties or published
- the audience for the outputs and reports
- where reports are to be published, the name of the publication.
- timeframes for the release of reports.

Human Research Ethics Committee (HREC)

Project proposals for health research will require:

- a full Human Research Ethics Committee (HREC) application for the projects if seeking to include Victoria, Queensland, New South Wales, Australian Capital Territory or Tasmania hospitals data. A single HREC will be mutually recognised across jurisdictions and sufficient to cover the project approval.
- If Victoria data is being utilised, the HREC must report to the Health Complaints Commissioner in Victoria as per the HPP research exemption guidelines 2.2G
- If ACT data is being used will need to request a governance approval from ACT Health.
- Link to National Mutual Acceptance Single Ethical Review of Multi-centre Research Projects List: HRECs,-RGOs-and-Organisations-March-2023.pdf (clinicaltrialsandresearch.vic.gov.au)

  Please attach details of these additional approvals.

Data custodian requirements

Approval by all members of the NHDH Advisory Committee and state and territory data custodians for data collections being used.

Commercial Gain

Please provide information on whether this project could be used for commercial gain.

Disclosure agreement

A description of your project may be included on the AIHW website.

Is there a non-discloser agreement on this project?

Yes No

Project leader

Name **Signature**	**Date**

AIHW Head of Ethics, Privacy and Legal Unit

I support the project noting the following, **Name** **Signature**	**Date**

NHDH Data Custodian

I support the project noting the following, **Name** **Signature**	**Date**

NHDH Advisory Committee member

Approved	☐	
Approved with conditions (please specify)	☐	
Not approved	☐	
Name		
Signature		**Date**

Attachment 5: HUB+n project proposal and conditions of use template – health research project

non-government organisations and analysts attached to universities or private research organisations.

Please keep the project proposal brief and delete instructions in blue when complete.

Refer to the National Health Data Hub (NHDH) *Governance protocols* for detailed information about the operation of the NHDH.

Project identifier

Assigned by the NHDH secretariat.

Project title

Auspicing/Funding bodies

If applicable, e.g., The Department of Health etc.

Please list main auspicing body and any other sources of funding for this project. If you are completing this form as part of a quote request for a grant application, please state what grant you are applying for and the submission deadline.

Organisation nominating the project.

E.g., NSW, Vic, Qld, University etc.

Project Type

e.g. Government led or non-government led.

Project leader/Principal Investigator

Include name, organisation, email address and phone number, and brief summary of experience/credentials.

Project Analysts

List intended analysts working on the project.

Include name, organisation, email address and phone number, and brief summary of experience/credentials. These are people who will require access to the secure environment in addition to the project leader.

The AIHW has embedded the *five safes framework* into our approach in making decisions about sharing and releasing data. Researchers will have the knowledge, skills and incentives to act in accordance with required standards of behaviour under the five safes framework.

These people will need to sign a s29 Confidentiality Undertaking (Attachment 2). It is the responsibility of the project leader to ensure the s29 Confidentiality Undertaking are signed.

Members of the research team who will access linked data must be physically located in Australia.

Project analysts and discussants

If applicable, please list other people or organisations (e.g., consultants) who will have access to project outputs and will discuss project outputs during the investigation phase of the project. These people will need to sign a s29 Confidentiality Undertaking (Attachment 2). It is the responsibility of the project leader to ensure the s29 Confidentiality Undertaking are signed.

Include name, organisation, email address.

Project advisors and other contributors

If applicable, please list other advisors or other contributors to the project. This may include peer review groups, committees, and external advisors These people will need to sign a s29 Confidentiality Undertaking (Attachment 2). It is the responsibility of the project leader to ensure the s29 Confidentiality Undertaking are signed.

Include name, Committee or group.

Project objective

What are the main objectives of the project? Please refer to the *Governance protocols* for intended uses of the NHDH.

Please indicate which states/territories hospitals data will be required for the project.

Please provide a headline statement describing the purpose of the linkage of your data set to the NHDH.

Default datasets or by exception datasets.

The NHDH data design uses ***default* data modules** and ***by exception* data modules.** The *by exception* data modules are characterised by containing the more sensitive data items such as exact/full dates for admission, separation, departure, presentation, referral, prescription, and service dates. Please note, the *default* data modules contain month and year of most dates but not the day of the date.

By exception data modules have been created for:

- All hospital content data modules
- MBS, PBS and NDI content data modules
- RAC and HCP aged care content data modules

Do you require access to by exception datasets.

No ☐

Yes ☐

If you have ticked yes. Please provide justification for access to the by exception data modules.

Collections used in the Project

Data modules	**Planned to be included in Analysis Yes/No**	**Are you requesting access to by exception data modules?** **Yes/No**
Patient Demographics: PATIENTS_DEMOGRAPHY	Yes (all researchers have access to this)	NA
ABS Country Classification Codes for Birth Country: SACC_CODES	Yes (all researchers have access to this)	NA
National Death data modules		
National Death Index: NDI_CONTENT		
Aged Care data modules		
Residential Age Care		N/A
Home Care		N/A
Home Support		N/A
Flexible Care		N/A
Aged Care Eligibility Assessment		N/A
Australian Immunisation Register data modules		
Child data modules: **Natural Immunity Details** (**Child**): AIR_CONTENT_NTRL_IMMNTY		

Medicare Contraindication Vaccines details (child): AIR_CONTENT_CNTRNDCTN **Vaccination Episodes that Individuals Received (Child)**: AIR_CONTENT_VACCNTN_EPSD		
Adult data modules: **Natural Immunity Details (Adult):** AIR_CONTENT_NTRL_IMMNTY **Medicare Contraindication Vaccines details (Adult):** AIR_CONTENT_CNTRNDCTN **Vaccination Episodes that Individuals Received (Adult):** AIR_CONTENT_VACCNTN_EPSD		
Vaccination Supply Details: AIR_DM_SUPPLR_VCCNE	Yes (all users have access to this when requesting AIR modules)	N/A
Antigen Codes and Vaccine Codes: AIR_DM_ANTGN_VCCNE_MP	Yes (all users have access to this when requesting AIR modules)	N/A
File Extract Information: AIR_CONTENT_PERSON_CURRENT	Yes (all users have access to this when requesting AIR modules)	N/A
COVID-19 Vaccination data: AIR_DM_CVD_CMPLNCE_STTS	Yes (all users have access to this when requesting AIR modules)	N/A
Antigen Codes and Antigen Names: AIR_DM_ANTGN	Yes (all users have access to this when requesting AIR modules)	N/A
Medicare Benefits Schedule		
Medicare Benefits Schedule (MBS): MBS_CONTENT		
Supplementary Data Speciality Codes: MBS_REG_SPECIALTY_CODES	Yes (all users have access to	N/A

	this when requesting MBS modules)	
Map of MBS Item Descriptions: MBS_ITEM_MAP	Yes (all users have access to this when requesting MBS modules)	N/A
Pharmaceutical Benefits Scheme		
Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS): PBS_CONTENT		
Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS) - Map of PBS Item Code Descriptions: PBS_ITEM_MAP	Yes (all users have access to this when requesting PBS)	N/A
Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS) - Supplementary Data Speciality Codes: PBS_DERIVED_MAJOR_SPECIALITY	Yes (all users have access to this when requesting PBS)	N/A
Will you be using Repatriation Pharmaceutical Benefits Scheme (RPBS) specifically to analyse the veteran/defence population use of pharmaceuticals Please state: Yes, No		
Hospital Data		
Hospital Data: HOSPITAL_CONTENT_DATA (Public hospital establishment information)	Yes (all users have access to this when requesting hospitals data listed below)	N/A

If the intention is to use all available states/territories then indicate in last row, otherwise place an X for each combination of hospitals collection and state/territory.

State/Territory	**Admitted Patient Care data** (AP_CONTENT)	**Non-Admitted Patient data** (NAP_CONTENT)	**Emergency Department Care data** (ED_CONTENT)	**Are you requesting access to *by exception***

				hospital data modules? Yes/No
NSW				
Vic				
Qld				
SA				
Tas				
ACT				
All available				

Project duration, and retention and destruction of data

Planned completion date.

DD/MM/YY

Archiving and Retention of data

As determined by section 2.3 of the Governance Protocols, files will be archived for seven years after the completion of the project unless a Human Research Ethics Approval (HREC) provides another period. Please provide the HREC period if different from section 2.3 of the protocols.

Consideration of community expectations

Please include details of how community expectations around the benefit project are being considered including plans and purpose for consultation with appropriate groups.

Please provide a brief summary description of the benefit of the linkage for the public or cohort.

- non-exhaustive list of examples Consultation with key stakeholders or client group representatives, for example via working groups or advisory groups
- public engagement such as broad public consultations
- use of focus groups
- engagement with expert groups
- information from engagement events for similar projects
- government initiatives
- public polls

- literature reviews. [1]

Projects with a First Nations people focus.

Will the project have a focus of analysis on the First Nations people population?

Yes No

If yes, project proposals should address how external advice from First Nations people is being sought and how appropriate consultation and oversight is provided during the life of the project.

Non-government research proposals where First Nations people are a focus must obtain a First Nations people Human Research Ethics Committee approval (HREC). For guidance in planning, designing, and conducting such research, please consult the NHMRC *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders 2018*, as well as the guidance provided by the First Nations people HRECs.

Outputs and reports

Please provide information on:

- whether jurisdictions will be identified in the outputs and reports
    - please specify jurisdictions and parent data collections being presented.
- whether individual entities (e.g., hospitals) will be identified in outputs and reports.
- whether comparisons of First Nations people and non-Indigenous people/other Australians/all Australians will be made in the outputs and reports
- whether outputs and reports will be distributed to third parties or published
- the audience for the outputs and reports
- where reports are to be published, the name of the publication.
- timeframes for the release of reports.

Please note: Unit record data is not allowed to be transferred outside of the Secure Access Environment

Human Research Ethics Committee (HREC) requirements

Project proposals for health research will require:

- a AIHW Human Research Ethics Committee (HREC) application, researchers must submit their projects to the AIHW Ethics Committee to ensure that their project

[1] https://uksa.statisticsauthority.gov.uk/wp-content/uploads/2019/05/2019_Self-assessment_guidance_V2.1.pdf, p. 15

complies with relevant legislation and requirements under the National Statement on Ethical Conduct in Human Research.

- If Victoria, Queensland, New South Wales, Australian Capital Territory or Tasmania hospitals data is being used, a single HREC application is required which will be mutually recognised across these jurisdictions via the National Mutual Acceptance Scheme. Link to National Mutual Acceptance Single Ethical Review of Multi-centre Research Projects List: https://www.clinicaltrialsandresearch.vic.gov.au/national-mutual-acceptance
- If Victorian hospital data is being utilised, a Victorian HREC approval is needed. This HREC must report to the Health Complaints Commissioner in Victoria as per the HPP research exemption guidelines 2.2G
- If ACT data is being used AIHW will request a governance approval from ACT Health on your behalf.

  Please attach details of these additional approvals.

Data custodian requirements

Approval by all members of the NHDH Advisory Committee and state and territory data custodians for data collections being used.

Commercial Gain

Please provide information on whether this project could be used for commercial gain.

Disclosure agreement

A description of your project may be included on the AIHW website.

Is there a non-discloser agreement on this project?

Yes No

Information on the data set to be linked to the NHDH.

Provide a description of the data set.

Will any content or cohort files to be supplied to AIHW include free-text fields?

Are there any time-critical aspects of the research project you would like us to be aware of? (e.g. funding expiry)

Expected date/s of supply of data to AIHW

Expected date/s of supply of linked data from AIHW

As defined in section 2.9 datasets that have less than 100,000 records will be assigned a data manager who will scope and cut the data manually. Please include information on how many records your dataset holds. Please provide information on who the data manager will be for this project (if required).

Cohort Specifications

Study cohort/s	
Did the cohort give consent to be part of your study? *Please attach consent forms/PIS when you return this form to AIHW DISC.*	EXPRESSED CONSENT ☐ OPT-OUT CONSENT ☐ NO CONSENT ☐
Did the cohort give consent to have their data/information linked? *Please attach consent forms/PIS when you return this form to AIHW DISC.*	EXPRESSED CONSENT ☐ OPT-OUT CONSENT ☐ NO CONSENT ☐
If unconsented, how are you proposing to satisfy the Australian Privacy Principles? *Please make specific references of how you will satisfy the requirements as detailed in the NHMRC National Statement.* *If you are requesting a waiver of consent pursuant to s.95 of the Privacy Act, please do not list what HRECs have already granted a waiver. You need to provide justification as to why the AIHW Ethics Committee should grant a waiver.*	
Please list the data collection/s or source(s) from which the study cohort will be derived.	
•	
Please describe the inclusion/exclusion criteria for the study cohort/s (including variables, dates)	
Estimated number of individuals	N =
Other information about the study cohort/s	
Personal identifiers for cohorts provided to the AIHW for linkage	

For studies where the cohort/s are not created by the AIHW, please list the personal identifiers (e.g. names, date of birth, sex, full address) or Statistical Linkage Key (SLK) information that will be provided to AIHW DISC either from you or another third party. *Best practice for probabilistic linkage is first name, last name, DOB, sex, address, postcode.*	
☐ Full name (including middle names if available)	☐ Death status and/or date of death
☐ Date of birth	☐ Date of diagnosis
☐ Sex	☐ Date of last contact
☐ Address	☐ Multiple births flag
☐ Postcode	☐ SLK-581
☐ Other (please specify):	

Control/comparator group/s	
Handy tip: When completing this section, please review the 'Comparator group advice' researcher resource on our website	
Is a control/comparator group part of your study?	YES ☐ NO ☐
Did the control/comparator give consent to be part of your study?	EXPRESSED CONSENT ☐ OPTOUT ☐ NO ☐
Did the control/comparator give consent to have their data/information linked?	EXPRESSED CONSENT ☐ OPTOUT ☐ NO ☐
If 'YES', who will create this group – e.g. AIHW, researchers, other linkage unit, other?	
Please list the data collection/s or source(s) from which the study control group/s will be derived.	
•	
Please describe the inclusion/exclusion criteria for the control group/s (including variables, dates)	

Estimated number of individuals	N =
Other information about the control/comparator group/s	
Personal identifiers for controls/comparators provided to the AIHW for linkage	
Please list only if these identifiers differ to those listed above for the study cohort	

Data Specifications

Data flow
Please outline the flow of 1) personal identifiers and 2) content data between data custodians, linkage unit/s and researchers. *Your AIHW linkage contact will help you format this section to align with AIHW standards.*
Researcher/data provider/state linkage team will provide: • e.g. Study content file and personal identifier file with project specific keys. AIHW will: • e.g. Receive study content file and personal identifier file with project specific keys under a by-law exemption to the Privacy Act 1988. • e.g. Study cohort linked to MBS/PBS data uploaded into SURE. • e.g. NDI file with project specific key to Researcher. Researcher will receive: • e.g. NDI file and save to access controlled directory on secure file server.

Data storage sites
Please list all the sites where any project-related data will be stored and a summary of security arrangements. *Where a project requires Medicare Benefits Schedule, Pharmaceutical Benefits Scheme, Centrelink, or certain other data, it is a data custodian requirement that the linked data set must be stored and analysed within an AIHW approved secure access environment (SAE)*

Data sets specifications

Data sets to be linked
Please list the data sets to be linked to the National Health Data Hub and the data provider. Please delete the rows for any data sets you are not requesting. If known, please indicate the legal mechanism you intend to utilise to authorise transfer of data to AIHW. If not, DISC will work with you to clarify this.

Data set	Data provider	Linkage or Content Data?	Legal Mechanism			
			Consent	Authorised by law	Waiver	De-identified
AIHW Health Spine or AIHW Health & Welfare Spine (Required)	AIHW	Linkage		x		
e.g. Cohort Personal Identifiers		Linkage				
e.g. Cohort Content Data		Linkage				
e.g. State/territory data sets						

Invoice details

Invoice details for feasibility questionnaire review fee	
As per our website, due to the effort involved in reviewing a feasibility questionnaire and preparing a quote, this service is subject to cost recovery. Please provide the requested details below. These details will only be used to invoice for the feasibility questionnaire review.	
Invoice recipient name:	

Invoice recipient position title:	
Invoice recipient postal address:	
Invoice recipient email:	

Data Integration Services Centre

Name	**Date**

Project leader

Name **Signature**	 **Date**

AIHW Head of Ethics, Privacy and Legal Unit

I support the project noting the following, **Name** **Signature**	 **Date**

NHDH Data Custodian

I support the project noting the following, **Name** **Signature**	 **Date**

NHDH Advisory Committee member

Approved ☐ **Approved with conditions (please specify)** ☐ **Not approved** ☐ **Name** **Signature**	 **Date**

Attachment 6: HUB+n project proposal and conditions of use template – government project

Please keep the project proposal brief and delete instructions in blue when complete.

Refer to the National Health Data Hub (NHDH)) *Governance protocols* for detailed information about the operation of the NHDH.

Project identifier

Assigned by the NHDH secretariat.

Project title

Auspicing body

If applicable, e.g., the Department of Health

Organisation nominating the project.

E.g., NSW, Vic, Qld etc.

Project leader

Include name, organisation, email address and phone number.

Project analysts and discussants

If applicable, please list other people or organisations (e.g., consultants) who will have access to project outputs and will discuss project outputs during the investigation phase of the project. These people will need to sign a s29 Confidentiality Undertaking (Attachment 2). It is the responsibility of the project leader to ensure the s29 Confidentiality Undertaking are signed. The AIHW has embedded the *five safes framework* into our approach in making decisions about sharing and releasing data. Researchers will have the knowledge, skills and incentives to act in accordance with required standards of behaviour under the five safes framework.

Include name, organisation, email address.

Project advisors and other contributors

If applicable, please list other advisors or other contributors to the project. This may include peer review groups, committees, and external advisors These people will need to sign a s29 Confidentiality Undertaking (Attachment 2). It is the responsibility of the project leader to ensure the s29 Confidentiality Undertaking are signed.

Include name, Committee or group.

Project objective

What are the main objectives of the project? Please refer to the *Governance protocols* for intended uses of the NHDH.

Please state whether Queensland hospitals data will be required for the project.

Project Methodology

What are the methodology approaches you plan to use in your projects? e.g how will cohorts be defined or outcomes be determined?

Default datasets or by exception datasets.

The NHDH data design uses ***default* data modules** and ***by exception* data modules.** The *by exception* data modules are characterised by containing the more sensitive data items such as exact/full dates for admission, separation, departure, presentation, referral, prescription, and service dates. Please note, the *default* data modules contain month and year of most dates but not the day of the date.

By exception data modules have been created for:

- All hospital content data modules
- MBS, PBS and NDI content data modules
- RAC and HCP aged care content data modules

Do you require access to by exception datasets.

No

Yes

If you have ticked yes. Please provide justification for access to the by exception data modules.

Collections used in the Project

Data modules	**Planned to be included in Analysis Yes/No**	**Are you requesting access to by exception data modules? Yes/No**
Patient Demographics: PATIENTS_DEMOGRAPHY	Yes (all researchers have access to this)	NA

ABS Country Classification Codes for Birth Country: SACC_CODES	Yes (all researchers have access to this)	NA
National Death data modules		
National Death Index: NDI_CONTENT		
Aged Care data modules		
Residential Age Care		N/A
Home Care		N/A
Home Support		N/A
Flexible Care		N/A
Aged Care Eligibility Assessment		N/A
Australian Immunisation Register data modules		
Child data modules: **Natural Immunity Details** (**Child**): AIR_CONTENT_NTRL_IMMNTY **Medicare Contraindication Vaccines details (child):** AIR_CONTENT_CNTRNDCTN **Vaccination Episodes that Individuals Received (Child)**: AIR_CONTENT_VACCNTN_EPSD		
Adult data modules: **Natural Immunity Details (Adult):** AIR_CONTENT_NTRL_IMMNTY **Medicare Contraindication Vaccines details (Adult):** AIR_CONTENT_CNTRNDCTN **Vaccination Episodes that Individuals Received (Adult):** AIR_CONTENT_VACCNTN_EPSD		
Vaccination Supply Details: AIR_DM_SUPPLR_VCCNE	Yes (all users have access to this when requesting AIR modules)	N/A
Antigen Codes and Vaccine Codes: AIR_DM_ANTGN_VCCNE_MP	Yes (all users have access to this when requesting AIR modules)	N/A

File Extract Information: AIR_CONTENT_PERSON_CURRENT	Yes (all users have access to this when requesting AIR modules)	N/A
COVID-19 Vaccination data: AIR_DM_CVD_CMPLNCE_STTS	Yes (all users have access to this when requesting AIR modules)	N/A
Antigen Codes and Antigen Names: AIR_DM_ANTGN	Yes (all users have access to this when requesting AIR modules)	N/A
Medicare Benefits Schedule		
Medicare Benefits Schedule (MBS): MBS_CONTENT		
Supplementary Data Speciality Codes: MBS_REG_SPECIALTY_CODES	Yes (all users have access to this when requesting MBS modules)	N/A
Map of MBS Item Descriptions: MBS_ITEM_MAP	Yes (all users have access to this when requesting MBS modules)	N/A
Pharmaceutical Benefits Scheme		
Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS): PBS_CONTENT		
Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS) - Map of PBS Item Code Descriptions: PBS_ITEM_MAP	Yes (all users have access to this when requesting PBS)	N/A
Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS) - Supplementary Data Speciality Codes: PBS_DERIVED_MAJOR_SPECIALITY	Yes (all users have access to this when requesting PBS)	N/A

Will you be using Repatriation Pharmaceutical Benefits Scheme (RPBS) specifically to analyse the veteran/defence population use of pharmaceuticals Please state: Yes, No		
Hospital Data		
Hospital Data: HOSPITAL_CONTENT_DATA (Public hospital establishment information)	Yes (all users have access to this when requesting hospitals data listed below)	N/A

If the intention is to use all available states/territories then indicate in last row, otherwise place an X for each combination of hospitals collection and state/territory.

State/Territory	**Admitted Patient Care data** (AP_CONTENT)	**Non-Admitted Patient data** (NAP_CONTENT)	**Emergency Department Care data** (ED_CONTENT)	**Are you requesting access to *by exception* hospital data modules?** Yes/No
NSW				
Vic				
Qld				
SA				
Tas				
ACT				
All available				

Project duration, and retention and destruction of data

Planned completion date.

DD/MM/YY

Archiving and Retention of data

As determined by section 2.3 of the Governance Protocols, files will be archived for seven years after the completion of the project unless a Human Research Ethics Approval (HREC) provides another period. Please provide the HREC period if different from section 2.3 of the protocols.

Consideration of community expectations

Please include details of how community expectations around the project are being considered including plans and purpose for consultation with appropriate groups.

Non-exhaustive list of examples

- Consultation with key stakeholders or client group representatives, for example via working groups or advisory groups
- public engagement such as broad public consultations
- use of focus groups
- engagement with expert groups
- information from engagement events for similar projects
- government initiatives
- public polls
- literature reviews. [1]

Projects with a First Nations people focus.

For any internal AIHW research with a First Nations people focus, advice would be sought from the Group Head of the First Nations people Group on potential sensitivities and whether it may also be appropriate to seek external advice from a First Nations people *expert.*

Please outline planned consultations with advisors who can support the appropriate and sensitive reporting of data.

Outputs and reports

Please provide information on:

- whether jurisdictions will be identified in the outputs and reports
    - please specify jurisdictions and parent data collections being presented.
- whether individual entities (e.g., hospitals) will be identified in outputs and reports.
- whether comparisons of First Nations people and non-Indigenous people/other Australians/all Australians will be made in the outputs and reports
- whether outputs and reports will be distributed to third parties or published
- the audience for the outputs and reports

[1] https://uksa.statisticsauthority.gov.uk/wp-content/uploads/2019/05/2019_Self-assessment_guidance_V2.1.pdf, p. 15

- where reports are to be published, the name of the publication.
- timeframes for the release of reports.

Data custodian requirements

Approval by all members of the NHDH Advisory Committee and state and territory data custodians for data collections being used.

Commercial Gain

Please provide information on whether this project could be used for commercial gain.

Disclosure agreement

A description of your project may be included on the AIHW website.

Is there a non-discloser agreement on this project?

Yes No

Information on the data set to be linked to the NHDH.

Provide a description of the data set.

Will any content or cohort files to be supplied to AIHW include free-text fields?

Are there any time-critical aspects of the research project you would like us to be aware of? (e.g. funding expiry)

Expected date/s of supply of data to AIHW

Expected date/s of supply of linked data from AIHW

As defined in section 2.9 datasets that have less than 100,000 records will be assigned a data manager who will scope and cut the data manually. Please include information on how many records your dataset holds. Please provide information on who the data manager will be for this project (if required).

Cohort Specifications

Study cohort/s	
Did the cohort give consent to be part of your study? *Please attach consent forms/PIS when you return this form to AIHW DISC.*	EXPRESSED CONSENT ☐ OPT-OUT CONSENT ☐ NO CONSENT ☐
Did the cohort give consent to have their data/information linked? *Please attach consent forms/PIS when you return this form to AIHW DISC.*	EXPRESSED CONSENT ☐ OPT-OUT CONSENT ☐ NO CONSENT ☐
If unconsented, how are you proposing to satisfy the Australian Privacy Principles? *Please make specific references of how you will satisfy the requirements as detailed in the NHMRC National Statement.* *If you are requesting a waiver of consent pursuant to s.95 of the Privacy Act, please do not list what HRECs have already granted a waiver. You need to provide justification as to why the AIHW Ethics Committee should grant a waiver.*	
Please list the data collection/s or source(s) from which the study cohort will be derived.	

•
Please describe the inclusion/exclusion criteria for the study cohort/s (including variables, dates)
Estimated number of individuals | N =
Other information about the study cohort/s

Personal identifiers for cohorts provided to the AIHW for linkage	
For studies where the cohort/s are not created by the AIHW, please list the personal identifiers (e.g. names, date of birth, sex, full address) or Statistical Linkage Key (SLK) information that will be provided to AIHW DISC either from you or another third party. *Best practice for probabilistic linkage is first name, last name, DOB, sex, address, postcode.*	
☐ Full name (including middle names if available)	☐ Death status and/or date of death
☐ Date of birth	☐ Date of diagnosis
☐ Sex	☐ Date of last contact
☐ Address	☐ Multiple births flag
☐ Postcode	☐ SLK-581
☐ Other (please specify):	

Control/comparator group/s	
Handy tip: When completing this section, please review the 'Comparator group advice' researcher resource on our website	
Is a control/comparator group part of your study?	YES ☐ NO ☐
Did the control/comparator give consent to be part of your study?	EXPRESSED CONSENT ☐ OPTOUT ☐ NO ☐
Did the control/comparator give consent to have their data/information linked?	EXPRESSED CONSENT ☐ OPTOUT ☐

	NO ☐
If 'YES', who will create this group – e.g. AIHW, researchers, other linkage unit, other?	
Please list the data collection/s or source(s) from which the study control group/s will be derived.	
•	
Please describe the inclusion/exclusion criteria for the control group/s (including variables, dates)	
Estimated number of individuals	N =
Other information about the control/comparator group/s	
Personal identifiers for controls/comparators provided to the AIHW for linkage	
Please list only if these identifiers differ to those listed above for the study cohort	

Data Specifications

Data flow
Please outline the flow of 1) personal identifiers and 2) content data between data custodians, linkage unit/s and researchers. *Your AIHW linkage contact will help you format this section to align with AIHW standards.*
Researcher/data provider/state linkage team will provide: • e.g. Study content file and personal identifier file with project specific keys. AIHW will: • e.g. Receive study content file and personal identifier file with project specific keys under a by-law exemption to the Privacy Act 1988. • e.g. Study cohort linked to MBS/PBS data uploaded into SURE. • e.g. NDI file with project specific key to Researcher. Researcher will receive: • e.g. NDI file and save to access controlled directory on secure file server.

Data storage sites
Please list all the sites where any project-related data will be stored and a summary of security arrangements. *Where a project requires Medicare Benefits Schedule, Pharmaceutical Benefits Scheme, Centrelink, or certain other data, it is a data custodian requirement that the linked data set must be stored and analysed within an AIHW approved secure access environment (SAE)*

Data sets specifications

Data sets to be linked
Please list the data sets to be linked to the National Health Data Hub and the data provider. Please delete the rows for any data sets you are not requesting. If known, please indicate the legal mechanism you intend to utilise to authorise transfer of data to AIHW. If not, DISC will work with you to clarify this.

Data set	Data provider	Linkage or Content Data?	Legal Mechanism			
			Consent	Authorised by law	Waiver	De-identified
AIHW Health Spine or AIHW Health & Welfare Spine (Required)	AIHW	Linkage		x		
e.g. Cohort Personal Identifiers		Linkage				
e.g. Cohort Content Data		Linkage				
e.g. State/territory data sets						

Invoice details

Invoice details for feasibility questionnaire review fee	
As per our website, due to the effort involved in reviewing a feasibility questionnaire and preparing a quote, this service is subject to cost recovery. Please provide the requested details below. These details will only be used to invoice for the feasibility questionnaire review.	
Invoice recipient name:	
Invoice recipient position title:	
Invoice recipient postal address:	
Invoice recipient email:	

Data Integration Services Centre

Name	**Date**

Project leader

Name **Signature**	 **Date**

AIHW Head of Ethics, Privacy and Legal Unit

I support the project noting the following, **Name** **Signature**	 **Date**

NHDH Data Custodian

I support the project noting the following, **Name** **Signature**	 **Date**

NHDH Advisory Committee member

Approved ☐ **Approved with conditions (please specify)** ☐ **Not approved** ☐ **Name** **Signature**	 **Date**

Attachment 7: Register of NHDH projects

Project register for the National Health Data Hub

Organisation	Purpose statement	Dissemination/Publication of reports (Y/N)	Plan for dissemination or publication of reports (if applicable)	Date of approval by NHDH Advisory Committee	Planned project end date	Current status (open/ closed)

Attachment 8: Register of NHDH analysts

Analysts register for the National Health Data Hub

Name of analyst	Organisation	Position title	Email address	Phone number	Name and phone number of secondary contact	Project ID(s) (can be multiple)	Signed AIHW Confidentiality undertaking provided to AIHW	Other Confidentiality undertakings signed (if applicable)	NHDH Access approval date	NHDH Access expiry date

Attachment 9: Analyst access forms for NHDH

Please delete instructions in blue when complete.

Project title

Project identifier

Allocated by the National Health Data Hub (NHDH) secretariat as part of project approval.

Analyst details

Include name, organisation, email address and phone number.

Mandatory training sessions are held once a month for new analysts using the NHDH. To receive an invitation to the next training session please email the NHDH@aihw.gov.au inbox.

- I have read and understood the *Governance protocols* document and understand conditions of use for the NHDH. ☐
- I have signed the AIHW Confidentiality undertaking. ☐

Applicant

Name **Signature**	**Date**

When completed for AIHW analysts or analysts using the RON please attach this form to your IT request. For Non-AIHW analysts please email this form to NHDH@aihw.gov.au

Attachment 10: NHDH Third party release template

Project identifier

Assigned by the National Health Data Hub (NHDH) secretariat as part of the Project proposal.

Project Title

Title as per the approved Project proposal.

Participating jurisdiction nominating the release.

E.g., Commonwealth Department of Health, NSW Ministry of Health, etc.

Project leader

Include name, organisation, email address and phone number.

Report/release summary

Please provide information on:

- source collections (MBS, PBS, NDI, Hospitals, RACS) presented in the release, or used as part of the methodology to generate outputs included in the release. This may include collections used in any inclusion/exclusion criteria, even where these data are not directly presented in outputs.
- whether state/territory hospitals data are presented in the release or used as part of the methodology to generate outputs included in the release. Please include the level of presentation (e.g., national, state of hospitalisation, state of usual residence, hospital, LHN, etc.) where applicable, and whether private hospitals data are included/presented.
- whether comparisons of First Nations people and non-Indigenous people/other Australians/all Australians will be made in the release
- the audience for the release (include name and organisation), and/or intention to publish into the public domain. Where reports are to be published, please include the name of the publication.
- timeframes for the release

Please attach a copy of the release material for review in-confidence by the NHDH Advisory Committee

Guidelines

1. Consequential suppressions must be applied to ensure that suppressed data cannot be derived from totals, and/or the combination of data in other cells and/or tables.
2. The release must be consistent with the purpose of the project and intended outputs and reports, as outlined in the approved project proposal.
3. All outputs used in the release must have received prior approval from the Data Custodian to be removed from the host environment. Outputs should be checked for quality assurance before seeking NHDH Advisory Committee approval for third-party release.

4. The release must comply with the AIHW Ethics Committee approved uses of the NHDH and the NHDH Governance protocols and comply with the confidentiality and privacy protections of the *AIHW Act 1987* and *Privacy Act 1988*.
5. Final third-party release must comply with any conditions specified by the NHDH Advisory Committee and/or the NHDH Data Custodian on approving the release.

Project leader

Name **Signature**	 **Date**

NHDH Advisory Committee member

Approved ☐ **Approved with conditions (please specify)** ☐ **Not approved** ☐ **Name** **Signature**	 **Date**

Attachment 11: Register of NHDH outputs

Output register for the National Health Data Hub

Name of analyst	Organisation	Project ID	Description of output	Request date	Approval date

When completed for AIHW analysts or analysts using the RON please attach this form to your IT request. For Non-AIHW analysts please email this form to NHDH@aihw.gov.au

Attachment 12: Output clearance request briefing AIHW National Health Data Hub

Please delete instructions in blue when complete.

Project identifier

Assigned by the National Health Data Hub (NHDH) secretariat as part of the Project proposal.

Please attach a copy of the completed Project proposal.

Project title

Analyst

Include name, organisation, email address and phone number.

Output summary

Please provide a summary of aggregate output tables to be released from Host environment, including the description, location in the host environment, and purpose in relation to the project objective.

Please outline the intended use of the output e.g., internal document, public release as report etc.

Guidelines

- Files must not contain unit record data about an individual.
- Files must not add information about a person or service event (including reference to person or row IDs held in other collections, e.g., Medicare no., de-identified record ID, etc.), and must not include information which may enable re-identification of an individual or an organisation.
- Files should be in MS Excel, comma separated values, text or another agreed file format (e.g., syntax can be transferred as text format). **Files must not be executable.**
- Files and their use should comply with the confidentiality and privacy protections of the *AIHW Act 1987*, *Privacy Act 1988*, and the NHDH Governance Protocols
- Files must be checked to ensure that they do not contain malicious content and will not cause damage to the NHDH or its host system.

NHDH Output checklist

Please fill in the form, indicate your response, and include the outputs as attachments.

Relevant metadata and classifications for all applicable reference years have been reviewed and implemented where appropriate.	☐ Yes	☐No	☐ NA
Methodology for analysis has been reviewed.	☐ Yes	☐No	☐ NA
Outputs are related to the project's goals as stated in the project proposal.	☐ Yes	☐No	☐ NA
Confirm that data analyses have been checked and confirmed against published data where possible.	☐ Yes	☐No	☐ NA
Release of requested program code from the host environment is saved as a text file and does not contain any data, describing any individual/organisation or observation from the data.	☐ Yes	☐No	☐ NA
Confirm that table titles, footnotes and other technical information are correct.	☐ Yes	☐No	☐ NA
SAS/program code and logs checked to ensure compliance with data analysis plan.	☐ Yes	☐No	☐ NA
Demographic disaggregation's presented are consistent with those outlined in the project proposal.	☐ Yes	☐No	☐ NA
Technical information provided in the briefing should include: • Description of scope, methodology used, including for example, inclusions, exclusions, and ICD codes used, and for complex methodologies, underlying counts that make up the calculation of the final number. • Clear explanatory notes or data dictionary details of items used. • Mapping files to be provided for non-standard geographic breakdowns. • Numerators and population denominators for rates where required. • Any association with previous requests clearly identified.	☐ Yes	☐No	☐ NA
Cell attribute check: Counts between 1 and 10 (<11) have been suppressed (this includes the suppression of measures, e.g., rates, with underlying counts between 1 and 10 (<11). Seek advice from the NHDH Data Custodian for permitted exceptions.	☐ Yes	☐No	

When completed for AIHW analysts or analysts using the RON please attach this form to your IT request. For Non-AIHW analysts please email this form to NHDH@aihw.gov.au

Consequential suppressions have been applied to ensure that suppressed data cannot be derived from totals, and/or from data in other cells and/or tables.	☐ Yes	☐No	☐ NA
Dominance check: Confirm that dominance check had been done. If yes, please provide location (i.e., URL) where the dominance check file had been saved: _____. **Applied to Hospital data, Aged care data, MBS data and PBS data.** National level data needs to be checked to see if a State or Territory is dominating the cell contribution, and State or Territory level data needs to be checked to see if a Hospital/Provider/Service is dominating the cell contribution. **For National level data**: To maintain confidentiality, reporting unit rules have been applied as per AIHW policy where: • If there are fewer than three States or Territories contributing to the cell, then the cell needs to be n. p'd and consequential suppression applied if required. • If there are three or more States or Territories contributing to the cell and one State or Territory contributes more than 85% of the total activities, then the cells need to be to be n. p'd (referred to as the 1,85 rule) and consequential suppression applied if required. • If there are three or more States or Territories contributing to the cell and two States or Territories contribute more than 90% of the total activities, then the cells need to be to be n. p'd (referred to as the 2,90 rule) and consequential suppression applied if required. **For State and Territory level data**: To maintain confidentiality, reporting unit rules have been applied as per AIHW policy where: • If there are fewer than three Hospitals/Providers/Services contributing to the cell, then the cell needs to be n. p'd and consequential suppression applied if required. • If there are three or more Hospitals/Providers/Services contributing to the cell and one Hospital/Providers/Services contributes more than 85% of the total activities, then the cells need to be to be n. p'd and consequential suppression applied if required.	☐ Yes	☐No	☐ NA

• If there are three or more Hospitals/Providers/Services contributing to the cell and two Hospitals/Providers/Services contribute more than 90% of the total activities, then the cells need to be to be n. p'd and consequential suppression applied if required			
Geography output checks: Minimum geographic area to be released is SA3. Cell attribute checks and Dominance checks still apply for geographic area outputs Note: Estimated denominator populations for geographical units by demographic specifications (e.g., age and sex), must be greater than 1,000. Analysts must ensure compliance of reporting unit rules for each geographical unit being outputted (e.g., State, Remoteness, SA3, etc.). Estimated populations are generally determined using ABS estimated population files.	☐ Yes	☐No	☐ NA
Model output checks: Regression coefficients and test statistics model check • Minimum 10 degrees of freedom • R-squared ≤ 0.8 (for linear regression models only) For regressions that include any categorical independent variables, check Rule of 10 and Dominance rules for all cells via crosstab of all the categorical independent variables (e.g., var1*var2*var3): • Rule of 10: Provide a crosstab of all the categorical independent variables. Each cell must have at least 10 observations. Note: If you do not meet this rule of 10, you need to suppress the intercept or some of the other coefficients of the model. • Dominance rules: Each cell in the crosstab needs to be tested for the (1,85 rule) and (2,90 rule) dominance rules (see dominance checks above for more information). Please provide location (URL) where the above checks file had been saved: _____. Note: If you are struggling to meet the criteria above, please contact the NHDH Data Custodian.	☐ Yes	☐No	☐ NA
Could the output be related to commercial gain	☐ Yes	☐No	

Analyst **Name** **Signature** **When signing this form, you are agreeing to the conditions listed in the s29 Confidentiality Undertaking.**	**Date**

When completed for AIHW analysts or analysts using the RON please attach this form to your IT request. For Non-AIHW analysts please email this form to NHDH@aihw.gov.au

Attachment 13: Input clearance request briefing National Health Data Hub

Please delete instructions in blue when complete.

Project identifier

Project title

Submitting analyst

Include name, organisation, email address and phone number.

Input summary

Please provide information on the file name and type requested for import.

Please give a brief description of the file, and how it will be used.

Guidelines

- Files must not contain unit record data about an individual.
- Files must not add information about a person or service event (including reference to person or row IDs held in other collections, e.g., Medicare no., de-identified record ID, etc.), and must not include information which may enable re-identification of an individual.
- Files should be in MS Excel, comma separated values, text or another agreed file format (e.g., syntax can be transferred as text format). **Files must not be executable.**
- Files and their use should comply with the confidentiality and privacy protections of the *AIHW Act 1987*, *Privacy Act 1988*, and the NHDH Governance protocols.
- Files must be checked to ensure that they do not contain malicious content and will not cause damage to the NHDH or its host system.

Additional Specifications:

- File location in RON/EDW: (Advise of the file path which you would like your file to be placed)
- Data Size (metadata):
- Data File Name (metadata):
- Date Data created (metadata):

Analyst

• **Name** • **Signature**	• **Date**

When completed for AIHW analysts or analysts using the RON please attach this form to your IT request. For Non-AIHW analysts please email this form to NHDH@aihw.gov.au

Attachment 14: Costs

Approved researchers can access the data available in NHDH for approved projects. Researchers will access the NHDH data via an AIHW managed instance of the Australian Bureau of Statistics (ABS) Secure Environment for Analysing Data (SEAD).

NHDH SEAD access fee schedule – 1 July 2023 to 30 June 2024 (all fees are exclusive of GST)

Annual project fees (cost per project) – standard and complex projects

Annual project fees (cost per project) – standard and complex projects

Items	SEAD
Project establishment • IT project set-up • Project approvals • Ongoing management • Onboarding training	$3000 AUD
Project curation • Ingress, egress, and external release approvals	$3000 AUD
Databrick (if required)	From $2500 AUD ^

Annual user fees (cost per researcher/analyst) – standard and complex projects

One-off project fees (cost per project) – standard and complex projects

Items	SEAD Costs
Project establishment • IT project set-up • Project approvals • Onboarding training	$3000 AUD

Annual project fees (cost per project) – standard and complex projects

Items	SEAD Costs
Project curation • Ingress, egress and external release approvals • Ongoing management	$3000 AUD
Databrick (if required)	From $5000 AUD^
Virtual machine • Set-up costs • Standard issue with CPU cores 8 and 64GB RAM • Access to office • Access to statao	$4180 AUD^
Access to SAS	$1250 AUD^

Access to office	NA – included in VM costs
Access to stata (optional)	NA – included in VM costs

Data linkage and extraction costs (cost per project) – complex projects only

Linkage feasibility review	From $2000 AUD
Bespoke linkage (per dataset cost)	From $19,500 AUD
Project scoping and subject matter expertise	From $2000 AUD

NA – not applicable

^ Direct costs AIHW are charged by ABS for SEAD environment

Please contact the NIHIS team via NHDH@aihw.gov.au to discuss your project and the charges that apply.

Attachment 15: Request for National Health Data Hub linkage: Technical Assessment

1. Introduction

1.1 Note for researchers

The AIHW Data Integration Services Centre (DISC) is committed to working together with researchers to:

- ensure that data requested for linkage will answer the proposed research questions
- ensure that study aims are achievable using the proposed linkage methodology
- successfully obtain AIHW Ethics Committee approval for their project.

To achieve these goals, all requests for linkage will undergo a technical assessment by AIHW DISC staff.

Please complete the **blue sections** of this technical assessment and return to linkage@aihw.gov.au.

Please use plain English. Responses should be succinct.

To avoid duplication, please read the form in its entirety before you begin completing each section.

Please do not attach a separate study protocol with your application. Please make sure all important study information is captured in this Technical Assessment form.

Please do not insert hyperlinks. Some members of the AIHW Ethics Committee only receive a paper copy.

References/citations are not required in this form. If you do wish to include them, please add them as an Appendix at the end of the Technical Assessment.

Following sign-off by DISC staff, researchers are invited to submit their projects to the AIHW Ethics Committee to ensure that their project complies with relevant legislation and requirements under the *National Statement on Ethical Conduct in Human Research*.

Please note that the AIHW Ethics Secretariat will not accept applications for AIHW Ethics Committee approval unless a technical assessment has been completed.

1.2 AIHW DISC use only

EO number	
Data sets to be linked by AIHW	
Linkage nodes involved	

1.3 Project details

Project Title	
Date of application	

1.4 Document version history. Please use whole numbers only for the version number.

Version	Author	Brief description of change/s e.g. amendment to variable lists; scope	AIHW DISC use only: Sign off date	Signed off by

1.5 Contact details		
Contact person		
Title and name		
Institution		
Institution address (and country if not Australia)		
Institution email		
Phone	Work:	Mobile:

1.6 Principal Investigator		
Please list the Principal Investigator who will lead projects accessing this linked data in the National Health Data Hub (NHDH). Investigators accessing AIHW supplied person-level linked data **must** be physically located in Australia and employed by an Australian institution/organisation.		
Principal Investigator		
Title and name		
Institution		
Institution address (and country if not Australia)		
Position title		
Institution email		
Phone	Work:	Mobile:
Qualifications, relevant skills, and experience (limit of 200 words).		

1.7 Lead institution details	
Name of lead institution	
Type of institution	☐ State or federal government agency ☐ University or research institute ☐ Government health service (e.g. public hospital) ☐ Private health service ☐ Other organisation (please describe):
Please complete this section if the lead institution **is a private sector health service or other organisation**	
Please provide a brief description of the private sector health service or other organisation, including its mission and aims (limit of 200 words)	

2. Project Details

2.1 Brief linkage summary
Please provide a brief summary description of the linkage project

Please provide details of your linkage project
The details outlined in this proposal should be the **same** as those approved or submitted for approval to an NHMRC-accredited human research ethics committee. **Linkage cohort** and **control group details,** and **data flow** are addressed in subsequent sections. **Privacy, dissemination of results, and data security** will be addressed in the **AIHW Ethics Committee** application.

Are you seeking approval for future linkages in this application? Further details are to be provided in Section 6.	☐ **YES**	☐ **NO**

How will this linkage facilitate research within the approved uses of NHDH
Information on approved uses of NHDH can be found here.
Benefits to the community of linking this data to NHDH

2.2 Funding

Please list all sources of funding for this linkage project. Please provide any deadlines/expiry dates for the funding. **Please provide further details if the sources of funding and/or participating organisation may be a conflict of interest.**

3. Project Information

3.1 Consent for data linkage

Handy tip
The AIHW Ethics Committee expects that whenever practicable, participant consent is obtained. This is particularly important for any future recruitment.

Did the cohort give consent to be part of your study?	☐ Express consent ☐ Opt-out consent ☐ No
Did the cohort give consent for linkage of their health records?	☐ Express consent ☐ Opt-out consent ☐ No
Did the cohort give consent to the use of their personal identifiers (full names, full date of birth, sex, and address if available) for linkage to the data sets of interest?	☐ Express consent ☐ Opt-out consent ☐ No
Did the cohort give consent to provide their personal identifiers to government agencies (e.g., AIHW) for linkage to their health data?	☐ Express consent ☐ Opt-out consent ☐ No

You will be asked to provide further details of the consent arrangements in your AIHW ethics application.

3.2 Linkage cohort/s

Please list the data collection/s or source(s) from which the linkage cohort will be derived.

•
Please describe the inclusion criteria for the linkage cohort/s (including variables, dates).
Please describe the exclusion criteria for the linkage cohort/s.

Estimated number of individuals (an estimated range is acceptable)	N =
Estimated number of records (if known)	N =

Other information about the linkage cohort/s

For studies where the cohort is not created by AIHW DISC, please mark all *identifiable variables* or *Statistical Linkage Key (SLK)* information that will be provided to AIHW DISC	
☐ Full name (including middle names if available)	☐ Death status and/or date of death
☐ Date of birth	☐ Date of diagnosis
☐ Sex	☐ Date of last contact
☐ Address	☐ Multiple births flag
☐ Postcode	☐ SLK-581
☐ Other (please specify):	

3.3 Control/comparator group/s

Handy tip
When completing this section, keep in mind that you will be able to define controls from Commonwealth data within NHDH, and please ensure you have read the 'Comparator group advice' researcher resource on the AIHW website.

Is a control/comparator group part of your study?	☐ **NO**	☐ **YES**
If 'YES', who will create this group – e.g. AIHW, researchers, other linkage unit, other?		
Please list the data collection/s or source(s) from which the study control group/s will be derived.		
•		
Please describe the inclusion criteria for the control group/s (including variables, dates).		
Please describe the exclusion criteria for the control group/s.		

Estimated number of individuals (an estimated range is acceptable)	N =
Estimated number of records (if known)	N =

Other information about the control/comparator group/s	
We have read the AIHW Ethics Committee advice about the size of comparator groups (please see: 'Comparator group advice' researcher resource on the AIHW website).	☐ **YES**
Please describe how you have met the recommended size limit or describe why you need to go above the recommended size limit for this project.	
Please list any identifiers to be provided to AIHW DISC if they differ to those listed above for the linkage cohort	

3.4 Data flow

Please outline the flow of 1) personal identifiers and 2) content data between data custodians, linkage unit/s and researchers
If you are unsure of the details, your AIHW linkage contact will help you complete this section.

Did you know…?

To minimise the risk of participant re-identification when data are to be stored in a secure access environment, a data linkage team will remove any original personal identification numbers and replace them with a new project-specific person number (PPN).

4. Non-NHDH Study data sets

4. Study data sets

Using the **Tables** on the next few pages, please:

- Select the content data **not included in NHDH** that are required from **national data collections**
- List the required content data from **state/territory government data collections**
- List the required content data from **other data sources.**
- Delete tables that are not required.

Please do not attach variable lists as separate documents. Lists of variables must be in Word format.

Please **list all variables and data sets** that will be accessed by the researchers.

If the variables of interest for the cohort differ to those required for the control group, please copy, and paste data set Tables as required (and clearly label).

Handy tip

Visit the AIHW website for more information about **Pharmaceutical Benefits Scheme, Medicare Benefits Schedule, National Death Index, Australian Cancer Database,** and other national data collections: **https://www.aihw.gov.au/about-our-data/our-data-collections**.

First Nations status and veteran status both have additional approval conditions.

If you would like to analyse and report on First Nations status, First Nations consultation and/or AH&MRC approval is required.

If you would like to analyse and report on Veteran status (including RPBS variables), DDVA HREC approval is required.

Please indicate if you would like to capture these variables and if you would like to report on these variables.

First Nations status	☐ Capture	☐ Report	☐ Neither
Veteran status	☐ Capture	☐ Report	☐ Neither

4.1 Commonwealth data sets (Not available through NHDH)

Commonwealth data set: Data Over Multiple Individual Occurrences (DOMINO) – Centrelink (updated August 2022)			
Please select the variables required from DOMINO *(available from 01/01/2000)*			
Data requested for the period	DD/MM/YYYY to DD/MM/YYYY		
Handy tips			
DOMINO data are available from 2000 onwards. Medical impairment data before 2002 are incomplete. DOMINO's interpersonal links function as follows: • A relative, such as child or partner of a Centrelink recipient has limited demographic data included if they are relevant to the recipient's payment • If that person is also a Centrelink customer, then details for their benefits are visible. Data in DOMINO tables are only presented or updated when relevant to their welfare payment. For relevant tables, a 'person ID', an 'event start date', and 'event end date' will also be provided. It is a Department of Social Services data custodian requirement that DOMINO data must be stored and accessed in a secure access environment. Please visit the AIHW DOMINO website for more information.			
Requested variables from the DOMINO tables below (☒ = selected variable)			
1. Benefit Determination Status		14. Housing Household Details	
Benefit Status	☐	Accommodation Type Code	☐
Client Benefit Type Code	☐	Home Ownership Type Code	☐
Recipient Deceased Flag	☐	Rent Type Code	☐
Duration of Episode (Days)	☐	Weekly Rent Paid	☐
End reason	☐	15. Business Income	
End reason code	☐	Annual Income from Non-Primary Production Business Assets	☐
2. Benefit Determination Health Care Cards		Annual Income from Primary Production Business Assets	☐
Event Actioned Date	☐	Annual Income from Real Estate Business Assets	☐
Concession Card Expiry Date	☐	Real Estate Income Valuation Codes	☐
Concession Card Issue Date	☐	Business Daily Earned Income	☐
Postcode listed on Concession Card	☐	Business Daily Unearned Income	☐
Concession Card Start Date	☐	16. Community Development Employment Projects (CDEP) Regular Income	
Concession Card State Code	☐	CDEP Fortnightly Income	☐
Carer allowance child Id	☐	CDEP Income Frequency Code	☐
Child Listed Id	☐	Synthetic Employer Id	☐
Number of Listed Children	☐	17. Community Development Employment Projects (CDEP) Other Income	
Concession Type Code	☐	CDEP Other Fortnightly Income	☐
Entitlement Type Code	☐	CDEP Income Frequency Code	☐
Foster Child Id	☐	Synthetic Employer Id	☐
Partner Listed Id	☐	18. Income from Defence Force Income Support Allowances	
Concession Card Pending Flag	☐	Client Benefit Type Code	☐
Card Issue Reason Code	☐	Defence Force Income Support Allowance Fortnightly Amount	☐

3. Benefit Determination Low Income Cards		19. Income from Department of Veterans Affairs Allowances	
Event Actioned Date	☐	DVA Fortnightly Income	☐
Concession Card End Date	☐	DVA Income Type	☐
Concession Card Issue Date	☐	20. Income from Continuous Employment	
Postcode listed on Concession Card	☐	Synthetic Employer Id	☐
Concession Card Start Date	☐	Fortnightly Income Amount from Continuous Employment	☐
Concession Card State Code	☐	Fortnightly Hours Worked in Continuous Employment	☐
Carer allowance child Id	☐	Employment Income Frequency	☐
Child Listed Id	☐	21. Income from Variable Employment	
Number of Listed Children	☐	Synthetic Employer Id	☐
Concession Type Code	☐	Fortnightly Income Amount from Variable Employment	☐
Entitlement Type Code	☐	Fortnightly Hours Worked in Variable Employment	☐
Foster Child Id	☐	Employment Income Frequency	☐
Partner Listed Id	☐	22. Senior Health Care Card Assessable Annual Income	
Concession Card Pending Flag	☐	Senior Health Care Card Annual Deemed Income	☐
Card Issue Reason Code	☐	Senior Health Care Card Annual Employed Benefit Income	☐
4. Benefit Determination Pensioner Concession Cards		Senior Health Care Card Annual Employed Benefit Income Flag	☐
Event Actioned Date	☐	Senior Health Care Card Annual Foreign Income	☐
Concession Card Expiry Date	☐	Senior Health Care Card Annual Taxable Income	☐
Concession Card Issue Date	☐	Senior Health Care Card Annual Taxable Income Estimate	☐
Postcode listed on Concession Card	☐	Senior Health Care Card Annual Property or Loss Amount	☐
Concession Card Start Date	☐	Senior Health Care Card Annual Salary Scarified Income	☐
Concession Card State Code	☐	23. Senior Health Care Card Assessable Annual Income	
Carer allowance child Id	☐	Income from Trust and Companies (annual)	☐
Child Listed Id	☐	24. Continuous Unearned Income	
Number of Listed Children	☐	Payment Benefit Type Code	☐
Concession Type Code	☐	Continuing Unearned Income – Compensation Income	☐
Entitlement Type Code	☐	Continuing Unearned Income – Foreign Income	☐
Foster Child Id	☐	Continuing Unearned Income – MIN/SIV/SAV Income	☐
Partner Listed Id	☐	Continuing Unearned Income – Other Government Payment	☐
Concession Card Pending Flag	☐	Continuing Unearned Income – Other Income	☐
Card Issue Reason Code	☐	Continuing Unearned Income – Superannuation	☐
5. Benefit Determination Senior Healthcare Cards		Continuing Unearned Income – Compensation Income Flag	☐

Event Actioned Date	☐	Continuing Unearned Income – Other Government Payment Flag	☐
Concession Card Expiry Date	☐	25. Variable Unearned Income	
Concession Card Issue Date	☐	Payment Benefit Type Code	☐
Postcode listed on Concession Card	☐	Task Code	☐
Concession Card Start Date	☐	Variable Unearned Income	☐
Concession Card State Code	☐	26. Location Boundaries Home Addresses	
Carer allowance child Id	☐	Address Type Code	☐
Child Listed Id	☐	Community Code	☐
Number of Listed Children	☐	Address Country	☐
Concession Type Code	☐	ASGS 2016 Meshblock	☐
Entitlement Type Code	☐	Address Postcode	☐
Foster Child Id	☐	Remote Indicator	☐
Partner Listed Id	☐	ASGS 2011 SA1 Main Code	☐
Concession Card Pending Flag	☐	ASGS 2011 SA2 Main Code	☐
Card Issue Reason Code	☐	Address State	☐
6. Education Undertaken		27. Location Boundaries Other Addresses	
Event Actioned Date	☐	Address Type Code	☐
Course Level	☐	Community Code	☐
Course Type Code	☐	Address Country	☐
Education Undertaken Episode Id	☐	ASGS 2016 Meshblock	☐
Institution Type	☐	Address Postcode	☐
Student Participation Status	☐	Remote Indicator	☐
7. Education Family Tax Benefit		ASGS 2011 SA1 Main Code	☐
Event Actioned Date	☐	ASGS 2011 SA2 Main Code	☐
Completion Date	☐	Address State	☐
Completion Indicator	☐	28. Medical Conditions Carees	
Year 12 Completion Indicator	☐	Adult Caree Medical Codes	☐
Course Level	☐	Child Caree Medical Codes	☐
Course Type Code	☐	Child Non-Recognised Disability Codes	☐
Institution Type	☐	Child Recognised Disability Codes	☐
Student Participation Status	☐	Terminal Illness Indicator	☐
8. Education Highest Level Obtained		THP ID	☐
Course Level Attained	☐	29. Medical Conditions Recipients	
Course Level Attained Description	☐	Activity Participation Code	☐
9. Education Entitlement Abstudy		Assessment Id	☐
Appropriation Code for Additional Assistance - Regular	☐	Channel Data Received	☐
Daily Amount for Additional Assistance - Regular	☐	Current Capacity Number	☐
Appropriation Code for Living Allowance / Board Provider	☐	Impairment Rating	☐
Daily Amount for Living Allowance / Board Provider	☐	Incapacity Period End Date	☐

Appropriation Code for Basic Payment	☐	Incapacity Exemption Indicator	☐
Daily Amount for Basic Payment	☐	Incapacity Period Start Date	☐
Appropriation Code for ABSTUDY Pensioner Education Supplement	☐	Incapacity Adjusted Work Hours	☐
Daily Amount for ABSTUDY Pensioner Education Supplement	☐	Manifestly Disabled Code	☐
Appropriation Code for ABSTUDY Pensioner Education Supplement	☐	Primary Medical Code	☐
Daily Amount for ABSTUDY Pensioner Education Supplement	☐	Secondary Medical Code Condition Code	☐
Appropriation Code for Pharmaceutical Allowance	☐	Secondary Medical Code Permanent Indicator	☐
Daily Amount for Pharmaceutical Allowance	☐	Temporary limited capacity period end date	☐
Appropriation Code for Remote Area Allowance / Board Provider	☐	Temporary limited capacity period start date	☐
Daily Amount for Remote Area Allowance / Board Provider	☐	Temporary reduction capacity period end date	☐
Appropriation Code for Remote Area Allowance	☐	Temporary reduction capacity hours	☐
Daily Amount for Remote Area Allowance	☐	Current capacity hours with intervention	☐
Appropriation Code for Rent Assistance / Board Provider	☐	30. Payment History One off payments	
Daily Amount for Rent Assistance / Board Provider	☐	Payment Benefit Type Code	☐
Appropriation Code for Rent Assistance	☐	Component Amount Paid (Daily)	☐
Daily Amount for Rent Assistance	☐	Payment Component Id	☐
Appropriation Code for Youth Disability Supplement	☐	Payment Component Type Code	☐
Daily Amount for Youth Disability Supplement	☐	31. Payment History Regular payments	
10. Education Entitlement Assistance for Isolated Children		Payment Benefit Type Code	☐
Appropriation Code for Additional Boarding Allowance	☐	Component Amount Paid (Daily)	☐
Daily Amount for Additional Boarding Allowance	☐	Payment Component Id	☐
Appropriation Code for Basic Boarding Allowance	☐	Payment Component Type Code	☐
Daily Amount for Basic Boarding Allowance	☐	32. Payment History Third Party payments	
Appropriation Code for AIC Pensioner Education Supplement	☐	Payment Benefit Type Code	☐
Daily Amount for AIC Pensioner Education Supplement	☐	Component Amount Paid (Daily)	☐
Appropriation Code for Second Home Allowance	☐	Payment Component Id	☐
Daily Amount for Second Home Allowance	☐	Payment Component Type Code	☐
11. Education Entitlement Education Entry Payment		33. Relationships Details	
Appropriation Code	☐	Relationship Type Code	☐
Education Entry Payment amount	☐	Relationship Person Id	☐
12. Education Entitlement Pensioner Education Supplements		34. Client Static Demographic Information	
Appropriation Code for Additional Assistance - Regular	☐	Client Age as of Extract Date	☐
Daily Amount for Additional Assistance - Regular	☐	Client Country of Birth Code	☐
Appropriation Code for ABSTUDY Pensioner Education Supplement	☐	Client Date of Birth	☐

Daily Amount for ABSTUDY Pensioner Education Supplement	☐	Client Date of Death	☐
Appropriation Code for FACS Pensioner Education Supplement	☐	Client Gender	☐
Daily Amount for FACS Pensioner Education Supplement	☐	Client Indigenous Code	☐
13. Education Entitlement Prior to 2001		Client Pension Blindness Start Date	☐
PEN (Pension) recipients' Daily CEPS (Centrelink Education Payment System) payment	☐		
Daily Amount for Additional Assistance - Regular	☐		

4.2 National data sets ACD: Australian Cancer Database

National data set: Australian Cancer Database (ACD)				
Handy tip				
Researchers must seek approvals from data custodians/ethics committees as required within **each jurisdiction**. **As it may take more than six months, researchers are advised to begin the approval process as soon as possible.**				
Please select the variables required from the ACD *(available from 1982)*				
Date range requested		☐ Earliest available year of diagnosis **to** latest available year of diagnosis **OR**		
		☐ Earliest available year of diagnosis common to all relevant cancer registries **to** latest available year of diagnosis common to all relevant cancer registries **OR**		
		☐ Other: DD/MM/YYYY to DD/MM/YYYY		
Jurisdictions requested	☐ Australian Capital Territory		☐ South Australia	
	☐ Queensland		☐ Tasmania	
	☐ New South Wales		☐ Victoria	
	☐ Northern Territory		☐ Western Australia	
Please list the types of cancers requested (dot point list is preferred)				
Please provide justification for the release of standard variables				
Please provide justification for <u>each</u> of the requested non-standard variables				
Requested ACD variables – ☒ = selected variable		= specific justification for release required		
Standard variables		**Non-standard variables (cancer registries also require justification for these variables)**		
Sex (sex)	☐	Date of birth (birth_date)	☐	
State of cancer registration (registry)^	☐	Date of birth accuracy indicator (birth_date_accuracy)	☐	
State/territory of residence at diagnosis (state)	☐	Indigenous status (subject to above) (Indigenous)	☐	
Date of diagnosis* (diagnosis_date)	☐	Country of birth (country_of_birth, country_of_birth_supp)	☐	
Date of diagnosis accuracy indicator (diagnosis_date_accuracy)	☐	Postcode at diagnosis (postcode)	☐	
Age at diagnosis (diagnosis_age)	☐	Statistical Local Area (2006) at diagnosis (SLA_2006)	☐	
Age group at diagnosis (diagnosis_age_group)	☐	Statistical Local Area (2011) at diagnosis (SLA_2011)	☐	

Date of death* (death_date)	☐	Statistical Area Level 2 (2011) at diagnosis (SA2_2011)	☐
Age at death (death_age)	☐	Statistical Area Level 2 (2016) at diagnosis (SA2_2016)	☐
Age group at death (death_age_group)	☐		
Site/type of cancer (ICD-10)	☐		
Most valid basis of diagnosis (best_basis)	☐		
Melanoma thickness (cutaneous melanomas) (breslow)	☐		
Size of tumour (breast cancers) (breast_tumour_size)	☐		
Topography (ICD-O-3) (topography)	☐		
Morphology (ICD-O-3) (morphology)	☐		
Underlying cause of death# (cause_of_death)	☐		

ACT Cancer Registry does **not** release date of birth and does not usually release postcodes.
^Note that ACT is combined with NSW; ACT and NSW registrations cannot be distinguished.
*ACT Cancer Registry usually only releases year of diagnosis and year of death. Month of diagnosis and month of death can be accessed if a strong justification is provided.
#Cancer Registry-coded cause of death code.

4.3 National data sets: National Diabetes Services Scheme (NDDS)

National data set: National Diabetes Services Scheme (NDSS)			
Please list the variables required from the NDSS *(available from January 1987)* For more information about the variables, the data dictionary for NDSS data supplied to AIHW can be requested.			
Data custodian		Diabetes Australia	
Data requested for the period		DD/MM/YYYY to DD/MM/YYYY	
Requested variables		**Variable description**	**Justification for the requested variable**
From ID	☐	Identifies which NDSS form version was used at the time of registration	
Sex	☐	Sex of NDSS registrant	
State/Territory of usual residence	☐	State or territory of residential/main address of NDSS registrant	
Postcode	☐	Postcode of residential/main address of NDSS registrant	
Postcode at diagnosis	☐	Postcode of residential/main address of NDSS registrant at time of diagnosis	
State at time of diagnosis	☐	State or territory of residential/main address of NDSS registrant at time of diagnosis	
Country at time of diagnosis	☐	Country of residential/main address of NDSS registrant at time of diagnosis	
Date of birth (MM/YYYY)	☐	Date of birth of NDSS registrant	
Indigenous status		Indigenous status of NDSS registrant	
Country of birth	☐	Country of birth of NDSS registrant	
Main language spoken at home	☐	Main language spoken at home of NDSS registrant	
Diagnosis date	☐	Date of diagnosis of NDSS registrant	
Time since diagnosis	☐	The approximate time expired since original diagnosis at the NDSS 'date of registration' as advised by NDSS	

		registrant. *Used where 'Diagnosis Date' is unknown.*	
Diabetes type	☐	NDSS registrants' diabetes type as advised by the certifying health professional on the NDSS registration form	
Doctor-Insulin required	☐	Does NDSS registrant requires insulin to treat diabetes as advised by the certifying health professional on the NDSS registration form	
Insulin type – injection	☐	Does NDSS registrant use injection method to administer insulin as advised by the certifying health professional on the NDSS registration form	
Insulin type – pump	☐	Does NDSS registrant use a pump to administer insulin as advised by the certifying health professional on the NDSS registration form	
Date of first insulin injection	☐	Date of first insulin use of NDSS registrant as advised by the certifying health professional on the NDSS registration form.	
First insulin approx. dates	☐	The approximate amount of time expired since original insulin injection at the NDSS 'date of registration' as advised by NDSS registrant. *Used where exact 'Date of First Insulin Injection' is unknown.*	
Non-insulin injectable allowed	☐	NDSS registrant authorised to be supplied with SHARPS for use with non-insulin injectable medication.	
Date first non-insulin injected	☐	Date of first non-insulin injectable medication use as advised by the certifying health professional on the NDSS registration form.	
Registration number [*scrambled*]	☐	Registration number of NDSS registrant	
Registration date	☐	Date registration details entered into database	
Date last modified	☐	Date the NDSS Registrant record last modified	
Status	☐	Status of NDSS registration.	
Status reason code	☐	Reason if Status = Not Current	
NDI match applied	☐	Whether the NDSS registrant has been flagged as deceased based on the NDI-match probability	
Date of death	☐	Date of death of NDSS registrant	
Member of GDM register	☐	Whether NDSS registrant has consented to being listed on the Gestational Diabetes Register registrant	
Date of last purchase	☐	Date of last purchase of product by NDSS registrant	
First purchase date	☐	This field is populated by a CodeUnit that run overnight to assess the first purchase date in the Posted Pre-Order Line database	
Date pump therapy commenced	☐	Date NDSS registrant was authorised to commence use of IPCs	
Diabetes treated by diet	☐	Method of treatment of Type 2 diabetes as indicated by the	

		certifying health professional at the time of registration	
Diabetes treated by exercise	☐	Method of treatment of Type 2 diabetes as indicated by the certifying health professional at the time of registration	
Diabetes treated by tablets	☐	Method of treatment of Type 2 diabetes as indicated by the certifying health professional at the time of registration	
GDM expiry date	☐	End date of 12 month NDSS registration period for all incidence of Gestational diabetes	
GDM start date	☐	Commencement date NDSS registration for all incidence of Gestational diabetes	
(GDM history) Date of birth	☐	Expected date of birth or actual date of birth of child born to woman with Gestational diabetes who register with the NDSS	
(GDM history) Date of death	☐	Date of death (where reported) of child born to woman with Gestational diabetes who register with the NDSS	
IPC category	☐	Category of insulin requiring registrant certified for insulin access	
Type of injectable required	☐	Type of non-insulin injectable medication used as advised by the certifying health professional	

4.4 Other Commonwealth/National data sets

Other Commonwealth/National data sets	
Name of Commonwealth/National data set:	
Data custodian:	
Copy and paste this table to add additional Commonwealth/National data sets as required. Please remove this row after pasting.	
Data requested for the period	DD/MM/YYYY to DD/MM/YYYY
Please provide a justification for the release of the requested variables	
Requested variables	**Justification**

4.4 State or territory data sets (not in the NHDH)

Note to researchers
You can provide us with exact copies of the state or territory variables lists submitted to the data custodian(s) as an appendix at the end of this form.

State or territory data sets

Name of state or territory data set:	
Data custodian:	
Copy and paste this table to add additional state or territory data sets as required. Please remove this row after pasting.	
Data requested for the period	DD/MM/YYYY to DD/MM/YYYY
Requested variables	

4.5 Other data sets that will be accessed by researchers

Other data sets that will be accessed by researchers (such as data sets provided by the research team)	
Name of other data set:	
Data custodian:	
Copy and paste this table to add additional other data sets as required. Please remove this row after pasting.	
Data requested for the period	DD/MM/YYYY to DD/MM/YYYY
Requested variables	

5. Data confidentiality, storage, and access safeguard

5.1 Participant re-identification risks
Please list any variables within the linked unit record data set, that when combined, may allow the re-identification of participants: e.g. date of birth, date of death, age, sex, gender, ethnicity, First Nations status, veteran status, marital status, country of birth, hospital names in rural areas, rare diseases in rural areas, postcode, other personal unique characteristics.
•
Why are these variables required to deliver project outcomes?

5.2 Additional safeguards	
During analyses, participant re-identification may occur where researchers have provided cohort information or work in the same organisation as the data custodian or provider. In addition to the s.29 *Undertaking of Confidentiality*, further safeguards are required in these circumstances	
Please acknowledge that cell sizes less than six (6) will not be included in any report or publication.	☐ **YES**

1. Where researchers have access to personal identifiers and content data for study participants, they will not access personal identifiers *and* content data at the same time for the duration of the project.

2. An independent data manager (not part of the research team) will be assigned and will be responsible for ensuring that personal identifiers and content data for participants are stored in separate data collections for the duration of the project. The independent data manager will also be responsible for ensuring that only approved investigators will access the data.

Please agree that these safeguards will be implemented for your study: ☐ **YES** ☐ **Not applicable**

Please complete the next question if the lead institution **is <u>NOT</u> a state or federal government agency.**

Please describe the lead institution's security policies and governance arrangements (including confidentiality agreements): i.e. are researchers required to sign undertakings to comply with the university's IT policy? Describe any training in confidentiality and privacy that are required.

Please do not describe your data storage security arrangements in this section. You will be asked to describe those arrangement in the online ethics (EthOS) application.

If applicable to your project, please describe any other re-identification safeguards that you will implement

5.3 Data storage sites

Please list all the sites where your project-related data will be stored..

Personal identifier data storage locations	*De-identified linked unit-record data storage locations*
•	• NHDH SAE •

Where additional content data or the personal identifiers of study participants are held outside SAEs, or held across multiple SAEs, researchers will have their access to this information suspended while they are working in the SAE.

Please agree that this safeguard will be implemented for your study. ☐ **YES** ☐ **Not applicable**

If 'YES', please describe the arrangements for suspension (e.g. IT access to researcher-held content data blocked for the duration of the study)

Did you know…?

If data sets are stored in a secure access environment *and* outside a secure access environment (e.g. a university network), personal identification numbers allocated by linkage units should be different. This ensures that it is not possible to make connections between the two environments and protects participant privacy.

Will any data stored and analysed within the secure access environment also be stored outside the secure access environment?	☐ **YES** ☐ **NO**

If 'YES', please list the data sets that will be stored in the two environments

If applicable to your project, please describe any other re-identification safeguards that you will implement

5.4 Requirements for data release by AIHW

Data release is subject to 1) data custodian <u>and</u> 2) AIHW Ethics Committee approvals

1. Data custodian suppression rules

Some data custodians may request that ALL data provided for the project comply with certain suppression rules, such as the provision of only month and year of birth (rather than date of birth), or the offsetting of all dates by a number of days known to the linkage teams but not the research team.

You must notify all relevant data suppliers when a data custodian has requested any suppression rules.		
Are any data custodian suppression rules in place for this project?	☐ **YES**	☐ **NO**
If 'YES', please list the data custodian and the suppression rules		
2. AIHW Ethics Committee approvals		
Please ensure you have listed all sensitive or potentially re-identifying variables in all data sets, including those provided by state or territory data custodians. This includes but is not restricted to First Nations status; full date of birth, date of death, dates of service or episode; postcode; or DVA status. If these variables are not approved by the AIHW Ethics Committee, your data file will not be accepted into the secure environment.		
I understand that data files may be rejected into secure environments where variables have not been approved by the AIHW Ethics Committee.	☐ **YES**	
Did you know?		
The variable lists in this application **MUST be the same as those provided to all data custodians**. If the variables lists do not match, you will be required to submit an amendment at your own cost. AIHW Ethics Committee will charge a complex amendment fee. AIHW DISC may also charge additional project support fees.		
I understand that the variable list in this application must be the same as those provided to all data custodians. If the variable lists do not match, I must complete an amendment at my own cost.	☐ **YES**	

5.5. Future extractions or linkages		
Handy tip		
A future extraction is where you require additional content data (i.e. more recent data) for the same cohort. **A future linkage** involves the inclusion of new study individuals, or the addition of a new content data set for the same or an expanded cohort. For future linkages involving new study individuals, the AIHW Ethics Committee expects that researchers will obtain consent for data linkage from participants where feasible. **Please only check 'YES' if you are seeking approval for the future extractions or linkages in this application.**		
Will future data extractions of non-NHDH data be required?	☐ **YES**	☐ **NO**
If 'YES', please list the data sets required		
•		
If 'YES', please provide details of the anticipated timing		
Will future linkages be required?	☐ **YES**	☐ **NO**
If 'YES', please list the data sets required		
•		
If 'YES', please provide details of the anticipated timing		
Will new individuals be submitted for future linkages?	☐ **YES**	☐ **NO**
Please describe the inclusion and exclusion criteria for new individuals		
Number of new individuals for each future linkage (an estimated range is acceptable)	N =	
Number of new records for each future linkage (if known)	N =	
What consent arrangements will be in place for any new study individuals?		

6. Principal Investigator declaration

6. Principal Investigator declaration	
Please complete this section once advised to by DISC	
• **I have reviewed and approved this application for national data to undertake health- or welfare-related research or evaluation.** • **I declare that approval from an NHMRC-accredited human research ethics committee is current or being sought for this linkage project.** • **I confirm that this Technical Assessment contains details of all data custodian requirements in terms of suppression rules. If a data custodian requests any additional suppression rules in the future, I will notify the AIHW linkage team.** • **I understand it is a data custodian requirement that once the secure access environment workspace contains any Commonwealth data, the AIHW will have sole curation rights.**	
Print name:	**Date of approval**:

7. AIHW Data Integration Services Centre use only

7.1 Linkage technical notes				
Client Services checks				
Discussed with linker	**Name**			
Linkage unit creating the master PPN				
Confirmation PPN with other nodes	**Email** ☐	**PHRN OAS** ☐	**Other** ☐	**N/A** ☐
Data flow agreed by nodes?	**YES** ☐ **NO** ☐ **N/A** ☐			
Reminder – two PPNs may be needed if data are also stored outside the secure access environment				

7.2 AIHW internal data custodian review

Minimum time required for internal review of commonly requested data sets:

- ACD – 2 weeks
- Screening data – 4 weeks
- DOMINO – 4 weeks
- SHSC – 6 weeks

These timeframes are a guide only and review may take longer. Data sets not listed may also require internal review.

Data collection	Data custodian name	Date reviewed

Appendix

- *Please delete title and this page if not required.*

Attachment 16: NHDH Project amendment

Section 1 – Project details

Project Identifier:

Project Title:

Project leader:

Name:

Email:

Phone:

Section 2 – Amendment details

(*tick one or more sections requested for amendment*)

☐Auspicing body

☐Participating jurisdiction

☐Project leader

☐Project contributors/Discussant

☐Moving to the NHDH *by exception* data modules

☐Project objective

☐Planned completion date

☐Vulnerable people

☐Outputs and reports

☐ Deactivate analysts access to SAE (e.g. left the analysis team)

Section 3 – Summary of changes

Project leader signature:_____ Date:____/____/_____

When completed for AIHW analysts or analysts using the RON please attach this form to your IT request. For Non-AIHW analysts please email this form to NHDH@aihw.gov.au

Section 4 – NHDH Secretariat to complete

Recommend amendment to be sent to NHDH Advisory Committee:

☐For information only ☐For approval ☐Not required

Comments:

Approvers

AIHW Head of Ethics, Legal and Privacy

Comments:

Signature:_____ Date:____/____/_____

NHDH Data Custodian

Comments:

Signature:_____ Date:____/____/_____

NHDH Advisory Committee member:

Comments:

Signature:_____ Date:____/____/_____

When completed for AIHW analysts or analysts using the RON please attach this form to your IT request. For Non-AIHW analysts please email this form to NHDH@aihw.gov.au