Northern Territory Aboriginal Health
Key Performance Indicator Information System

Australian Government
Department of Health

AMSANT

Northern Territory Government

Northern Territory Aboriginal Health Key Performance Indicators

Data Release Protocol

May 2021

Version 2.9

Document title	Northern Territory Aboriginal Health Key Performance Indicators Data Release Protocol
Approved by	Aboriginal Health Forum
Date approved	
Document review	Two years from date of approval

Version	Date	Author	Changes made
1.1.2 – 2.8	15 October 2007 to 18 December 2014	Various	Refer to NT AHKPI Data Management Policy

2.9	23 April 2021	Amanda Lanagan	• Split out from Data Management Policy
			• Update to reflect 'Release' rather than 'Access'
			• Incorporate feedback from DCDD Health Data Governance Manager (refreshed form and request flow)
			• Incorporate feedback from AHKPI Steering Committee members:
			   o Add caveats on identification of communities and health services
			   o Strengthen elements of the Data Release Form

Acronyms	Full form
ACCHO	Aboriginal Community Controlled Health Organisation
AHF	NT Aboriginal Health Forum
AHKPI	Aboriginal Health Key Performance Indicators
DCDD	NT Government Department of Corporate and Digital Development
HREC	Human Research Ethics Committee
HSDA	Health Service Delivery Area
NT	Northern Territory

Contents

Introduction

The Northern Territory Aboriginal Health Key Performance Indicator (NT AHKPI) Management Policy is supported by, and underpins, this Data Release Protocol.

This Data Release Protocol details the processes by which NT AHKPI data and reports may be approved for release to authorised users. The protocol aims to:

1. Eliminate the risk of releasing identifiable information about individuals, communities or health centres.
2. Facilitate availability of aggregated and de-identified data to assist in evidence-based service monitoring, planning, decision-making and Continual Quality Improvement activities.

Potentially identifiable data

Identifying information relating to individual clients will not be included in any NT AHKPI data approved for release by the NT AHKPI Steering Committee.

NT AHKPI data sets in which individuals, communities or health centres might be identified will only be provided with the authority of the appropriate Community Data Owner (i.e. within the relevant Government or Aboriginal Community Controlled Health Organisation (ACCHO) service provider). A health service provider may also choose to seek endorsement for the release of the data from their community/s.

Release of NT AHKPI reports

NT Aboriginal Health Forum partner organisations

As the Data Collection Owner, the NT AHF partner representatives can access copies of de-identified Health Service Delivery Area (HSDA) reports (without population figures), and will automatically receive NT-wide NT AHKPI reports. Any de-identified HSDA level and NT-wide NT AHKPI reports provided to NT AHF representatives cannot be shared with any external organisation or group or with the public unless there has been prior public release of the data by the NT AHF or agreement to the release by the AHKPI Steering Committee.

NT-level KPI reports are automatically generated twice per annum from the NT AHKPI system and delivered directly to the NT AHF via the NT AHF secretariat. NT AHF partner representatives are responsible for the security and appropriate use of the NT AHKPI data (refer "Background" in Data Management Policy) within their respective organisations.

Access to NT AHKPI data or reports within NT AHF partner organisations will be determined on a 'need to know' basis for the purposes of evidence-based monitoring, planning and policy development. Where representatives are unsure about the application of these principles and standards, they should seek the advice of the AHKPI Steering Committee and, if necessary, complete a Data Release Approval Request form for consideration by the Steering Committee.

If a NTAHF partner organisation wishes to release AHKPI data or reports, a NT AHKPI Data Release Request Form must be completed and submitted to the AHKPI Steering Committee.

A Data Release Request Form must also be filled out by NT AHF partner organisations seeking customised or one-off NT AHKPI data reports.

"Mixed model" health centres

Some community level health centres are serviced by two health provider organisations, which each employ staff who are responsible for collecting and reviewing NT AHKPI data in that health centre. Once formal authorisation to access data from each organisation has been documented, the designated Community Data Owner for the respective organisations will automatically receive NT AHKPI aggregated data reports for that health centre/community. The ongoing automatic delivery of the reports in mixed model health centres has the potential to facilitate increased linkages and coordination through more effective analysis and use of data and Continual Quality Improvement activities.

Organisations that auspice the delivery of services on behalf of a governance body in mixed model health centres must ensure that they have been authorised to automatically receive copies of the reports from both providers in the centre.

Release of data or reports to other organisations or individuals, including researchers

Individuals, organisations or research teams seeking NT AHKPI aggregated data or reports are required to complete a NT AHKPI Data Release Request form. The form requires them to outline how the data will be used to:

- Inform understanding of trends in individual and population health outcomes;
- Identify factors influencing these trends; and
- Inform appropriate action, planning and policy development.

The completed NT AHKPI Data Release Request Form must be accompanied by a copy of the research proposal and, where appropriate evidence of ethics approval, and submitted to the NT AHKPI Data Custodian.

The form will first be considered by the NT AHKPI Data Custodian who may seek further information to support the request.

Management of Approved Data Release Requests

The NT AHKPI Data Custodian will only deliver NT AHKPI data to approved recipients. The Data Custodian is the primary contact for those seeking access to NT AHKPI data stored in the NT DoH Data Warehouse.

On receipt of a completed NT AHKPI Data Release Form, the NT AHKPI Data Custodian:

- Considers whether the reasons for requesting the NT AHKPI data satisfy Information Privacy Principles;
- Verifies that the requested NT AHKPI data is held in the Data Warehouse and provides feedback to the applicant on NT AHKPI data quality and date range availability;
- Verifies that any proposed research using the data has been approved by a Human Research Ethics Committee as appropriate;

- Ensures that appropriate approval has been given by the relevant service provider Community Data Owner or by the NT AHKPI Steering Committee as the delegated Collection Data Owner;
- Provides advice to the health service provider Community Data Owner/s or the NT AHKPI Steering Committee on whether the request should be approved.

According to the nature of the request, Community Data Owners may apply caveats on the release of their organisation's NT AHKPI data, or may delegate their approval.

Following the approvals process, the NT AHKPI Data Custodian is responsible for managing and scheduling the data management work required to deliver the NT AHKPI data to the approved recipient. This may involve the Data Custodian obtaining a Quality Assurance endorsement from the health service provider Community Data Owner/s, or coordinating new data mart development in order to deliver NT AHKPI data.

The DCDD NT AHKPI team is responsible for extraction, formatting and secure delivery of the data or report.

Data release approval

Appendix 1 provides a Data Release Approval Flow Chart that summarises the approval process.

Publication

As per the NT AHKPI Data Request Form, Section 11 Agreement:

> Any publication or presentation that uses the requested data will correctly attribute the origin of the data, and will include specific caveats or comments as directed by the NT AHKPI Steering Committee (the Data Collection Owner) or health service provider Community Data Owner/s *(if applicable)*.

The data recipient is required to agree that, prior to any publication of NT AHKPI data, the Community or Collection Data Owner/s will be given the opportunity to review and comment on the recipient's interpretation of results, and that these comments will be included in the report.

Where there is reasonable concern that specific communities or health centres may be identifiable through a report which will be publicly released, the relevant health service provider Community Data Owner/s have the right to refuse permission to publish their organisation's data or reports.

In addition, all parts of the Conditions of publication must be followed.

NT AHKPI system management team

The NT AHKPI Data Custodian (Senior Reporting Analyst, Health Reporting and Analytics, DCDD) is responsible for facilitating access to data or reports where authorised by the NT AHKPI Data Collection Owner (delegated to NT AHKPI Steering Committee) or by Community Data Owners. All NT DCDD staff sign an undertaking of confidentiality and only staff involved with the system have access to the data.
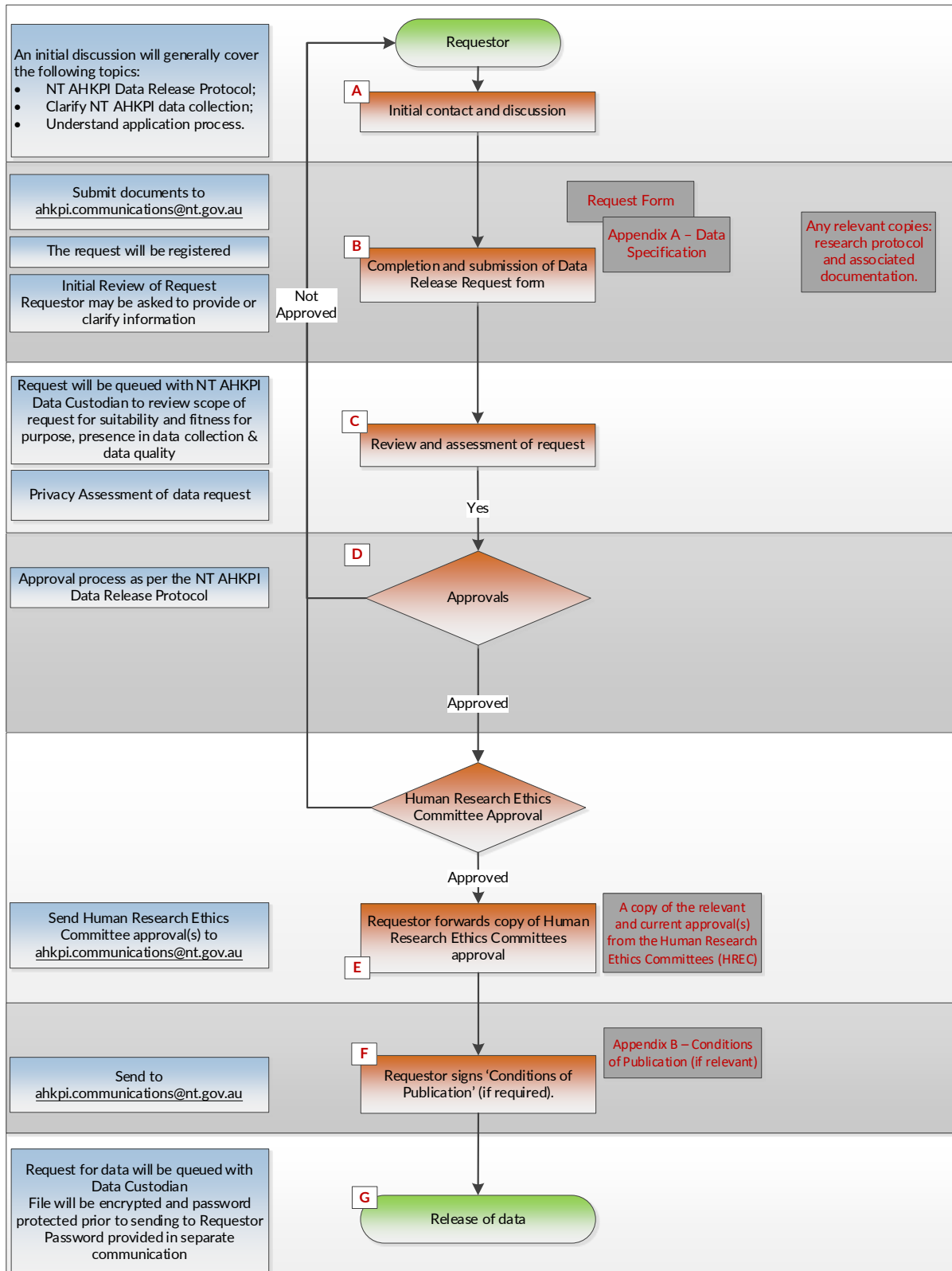
Appendix 1

Request for Data Release

Step	Action	Responsibility
A. Initial Contact and Discussion	• Initial contact, discussion and scoping with Data Custodian to determine data exists, is appropriate and is available.	Requestor
B. Generation of Request for Data Release	• Completion of "Data Release Request" form with submission to NT AHKPI Data Custodian.	Requestor
C. Review and Assessment	• Assess the request in terms of privacy, data fitness for purpose and data availability, with findings documented in the "Review and Approval" form.	Data Custodian
D. Obtain Approvals	• Obtain approvals from relevant Community Data Owner(s) (as required) • Obtain approval from Data Collection Sponsor (NT AHKPI Steering Committee)	Data Custodian / Data Owners
E. HREC Approval	• Human Research Ethics Committee approval if required.	Requestor
F. Conditions of Publication	• Sign "Conditions of Publication" (if relevant)	Requestor
G. Delivery of Data	• Extraction and delivery of data.	Data Custodian

Data Release Approval Flow Chart

The following workflow outlines the data release process for a data request.

Requestor

A — Initial contact and discussion

An initial discussion will generally cover the following topics:
- NT AHKPI Data Release Protocol;
- Clarify NT AHKPI data collection;
- Understand application process.

B — Completion and submission of Data Release Request form

Submit documents to ahkpi.communications@nt.gov.au

The request will be registered

Initial Review of Request Requestor may be asked to provide or clarify information

Request Form

Appendix A – Data Specification

Any relevant copies: research protocol and associated documentation.

Not Approved

C — Review and assessment of request

Request will be queued with NT AHKPI Data Custodian to review scope of request for suitability and fitness for purpose, presence in data collection & data quality

Privacy Assessment of data request

Yes

D — Approvals

Approval process as per the NT AHKPI Data Release Protocol

Approved

Human Research Ethics Committee Approval

Approved

E — Requestor forwards copy of Human Research Ethics Committees approval

Send Human Research Ethics Committee approval(s) to ahkpi.communications@nt.gov.au

A copy of the relevant and current approval(s) from the Human Research Ethics Committees (HREC)

F — Requestor signs 'Conditions of Publication' (if required).

Send to ahkpi.communications@nt.gov.au

Appendix B – Conditions of Publication (if relevant)

G — Release of data

Request for data will be queued with Data Custodian
File will be encrypted and password protected prior to sending to Requestor
Password provided in separate communication

NT AHKPI Data Release Request Form

All requests for the use of the Department of Health's data for the purpose of research must have the approval of a Human Research Ethics Committee, depending on the research and the population to be covered by the research.

Form Instructions

The information required from the researcher is provided in italics. This information should be inserted into the corresponding boxes, which may be expanded as required. Completed applications are to be submitted to the NT AHKPI Helpdesk (ahkpi.communications@nt.gov.au) with the relevant attachments.

Data Definitions

A copy the NT Aboriginal Health Key Performance Indicators – Definitions should be reviewed prior to placing any request as they outline the data availability.

File Format

Data will be provided in an agreed format, generally as a delimited or fixed width text file or in MS Excel, depending on file size. All files transmitted externally to the NTG network or email will be encrypted and password protected, with the password provided separately to the file.

1. Project Title

2. Project Summary

Broadly describe the purpose and objectives of the project.

3. Contact Details

3.1 Principal Investigator

This must be the person who has overall responsibility for the management of the project and must <u>not</u> be a student. The Principal Investigator must read and sign the declarations at the end of this form.

Name	
Position title	
Section / Branch / Organisation	
Organisation Type	☐ NT Department of Health ☐ Other non-government organisation ☐ Other NT Government ☐ Commonwealth Department /Agency ☐ Research organisation
Address	
Telephone	
Email	
Briefly outline experience of the principal investigator or team in Aboriginal and Torres Strait Islander research	

3.2 Project Contact	
This should be the person to be contacted for queries regarding this project.	
Is the contact the same as above?	☐ Yes ☐ No
Name	
Position title	
Section / Branch / Organisation	
Address	
Telephone	
Email	

4. Publication

Results with a cell count of less than five or a denominator less than 10 will not be published or disseminated in any way. Conditions for Publication will reflect publication restrictions and will be required to be signed before data can be supplied.

Results to be published in the public domain?	☐ Yes ☐ No
Results to be published on an intranet or internal bulletin?	☐ Yes ☐ No

Explain how statistics or results will be disseminated e.g. report, publication, conference, thesis. Describe how confidentiality of participants, health services / communities will be maintained in the dissemination of results.

5. Summary of Data

Describe the data to be used in your project.

6. Relevance of request to NT AHKPI collection goal

The goal of the NT AHKPI data collection is:

> *To improve Primary Health Care services for Indigenous Australians in the NT by building capacity at the service and system levels to collect, analyse and interpret data to:*
> - *Inform understanding of trends in individual and population health outcomes;*

- *Identify factors influencing these trends; and*
- *Inform appropriate action, planning and policy development*

Describe how the information being sought will be used to support this goal.

| |
| |

7. Outline of Project

Please provide an outline of your project including the background, aims and design and methodology.

Background	
Aims	
Design	
Methodology	
Dissemination of results back to health services and to NT AHKPI Steering Committee	

8. Security Plan

In compliance with the Information Act (IPP4 Data security), the Department of Health is required to take reasonable steps to ensure personal information it holds is protected from misuse and loss and from unauthorised access, modification or disclosure. Where the release of data has been authorised for a particular purpose, applicants are obliged to destroy personal information when it is no longer needed for that stated purpose.

Provide a detailed security plan setting out how the data will be protected

| |

9. Data Retention And Disposal Plan

I will ensure that all copies of the data are destroyed within seven years, or earlier, of publication or release of findings or, where no publication occurs, within seven years or earlier of receipt of the data, with Department of Health notified in writing once this is completed.

Period of data retention	
Describe how the data will be disposed of	

10. Ethics Review

Health Research may or may not require approval from a Human Research Ethics Committee (HREC).

Is HREC approval required?	☐ Yes ☐ No
HREC approval has been sought?	☐ Yes ☐ No
HREC approval has been given?	☐ Yes ☐ No

10.1 HREC Approval

If a HREC application(s) have been made, please fill in details here. Attach additional copies of this page if required. Copies of submission and approval documents will be required to support the data request. Any supporting HREC information must be provided before data can be supplied.

HREC Name	
HREC Approval Reference	
NHMRC Registration No. *(if applicable)*	
HREC Approval Date	
HREC Approval Period	
HREC Name	

11. Agreement

11.1 Applicant / Principal Investigator

Tick the boxes to indicate that you have read and understood each clause.

I the *Applicant/Principal Investigator* certify that;

☐   All information in this application is truthful and as complete as possible.

☐   I am aware of and understand the relevant legislation and regulations, and the project will be conducted in accordance with these.

    The information sought will be used solely for the purpose of undertaking this project/activity.

☐   Where the approval of the Data Collection Owner or health service provider Community Data Owner/s is given for the release of data or information, adequate opportunity for review and comment will be provided.

☐   Any publication or presentation that uses the requested data will correctly attribute the origin of the data, and will include specific caveats or comments as directed by the NT AHKPI Steering Committee (the Data Collection Owner) or health service provider Community Data Owner/s. *(if applicable).*

I acknowledge that the de-identified data provided for this project by the Data Custodians are Confidential Information and that I am responsible for ensuring that the information will be kept confidential.

Full Name (Printed)	
Signature	
Date	

Appendix A – Data Specification

Project Title	
Collection Period of Data FROM	**Collection Period of Data TO**

NT Aboriginal Health Key Performance Indicators		
Indicator Name	**Since**	**Select**
1.1 Episodes of Health Care and Client Contacts	2010	☐ Yes
1.2.1 First Antenatal Visit	2010	☐ Yes
1.2.2 Anaemia in Pregnancy	2019	☐ Yes
1.3 Birth Weight	2010	☐ Yes
1.4.1 Fully Immunised Children	2010	☐ Yes
1.4.2 Timeliness of Immunisations	2013-14	☐ Yes
1.5 Underweight Children	2010	☐ Yes
1.6 Anaemic Children	2010	☐ Yes
1.7 Chronic Disease Management Plan	2010	☐ Yes
1.8.1 HbA1c Tests	2010	☐ Yes
1.8.2 HbA1c Measurements	2013-14	☐ Yes
1.9 ACE Inhibitor and/or ARB	2010	☐ Yes
1.10 Adult Aged 15 - 54 Health Centre	2010	☐ Yes
1.11 Adult Aged 55 and over Health Centre	2010	☐ Yes
1.12 Pap Smear Tests	2010	☐ Yes
1.13 Blood Pressure Control	2013-14	☐ Yes
1.14 Chronic Kidney Disease	2014	☐ Yes
1.15 Rheumatic Heart Disease	2013-14	☐ Yes
1.16 Tobacco Use	2014	☐ Yes
1.17 Sexually Transmissible Disease	2014-15	☐ Yes
1.18 Cardiovascular Risk Assessment	2015-16	☐ Yes
1.19 Diabetic Retinopathy	2015-16	☐ Yes
1.20 Ear Disease in Children	2017	☐ Yes

Appendix B – Conditions of Publication

A. The data file will not be matched, in whole or part with any other information for the purposes of attempting to identify individuals, specific communities or health services, nor will any other attempt to identify an individual or community be made.

B. The data will not be disclosed or released to any other person or organisation, except as statistical information that does not identify or is not capable of being used to reasonably ascertain the identity of an individual, community or health service.

C. The information will be used for statistical purposes.

D. The information will not be used as a basis for any legal, administrative or other actions that could directly affect any particular individual or organisations as a result of their identification in this project.

E. The recipient will comply any relevant Privacy Principles and laws of the Northern Territory and Australian Governments.

F. The data file is provided solely to the recipient and must not be communicated to other persons or organisations, linked with files of personal information of other sources, except where the prior express authorisation to do so has been obtained from the NT AHKPI Steering Committee.

G. Data files are to be maintained and stored in a secure manner in an environment where they cannot be linked (either electronically or by personal inspection) with other patient records or patient level data or personal information.

H. When no longer required, the data files are to be destroyed.

I. Published results of any data analysis will protect the identity of individual patients and individual establishment (counts less than 5 shall be suppressed).

J. The data will not be used for any other purpose other than that specified in the approved request and will not be linked to any other data.

K. Any breach of the conditions or breaches of security of the data or other relevant circumstances relating to the data must immediately be notified to the NT AHKPI Steering Committee.

Project Name		
Requestor		
Full Name (Printed)		
Position		
Organisation		
Signature	**Date**	

Appendix C – Review and Approval

Project Title	

Section 1: Requested Data

Scop of data	
Required KPIs indicated and date range indicated?	☐ Yes ☐ No
Comment:	

Scope for publication	
Results to be published in the public domain?	☐ Yes ☐ No
Comment:	

Data assessment	
Fitness for purpose of requested variables and selection criteria?	☐ Yes ☐ No
Comment:	

Section 2: Privacy Review

This section is completed by the NT AHKPI Data Custodian.

Privacy		
Organisation *'Health Services/Clinics'*	N/A ☐ Low ☐ Medium ☐ High ☐	
The following research variables have the potential to identify an organisation directly.		
Individual Service Name		☐ Yes
Individual Clinic Name		☐ Yes
Community *'Postcode/Suburb/Town/Community'*	N/A ☐ Low ☐ Medium ☐ High ☐	
The following research variables have the potential to identify a community directly.		
Location Name (Suburb / Town / Community)		☐ Yes
HSDA		☐ Yes
Region		☐ Yes

Caveats / conditions on requested variables

Comments

NT AHKPI Data Custodian _____ Endorsement ☐ Yes ☐ No

Signature _____ Date __ / __ / 2021

Section 3: Approval

I have read the material set out in this application and approve access to the information requested for the purpose of this project/activity in accordance with, and subject to, the methodology and measures set out in the and subject to the general conditions in the Data Request and any Caveats, Conditions and data limitation Solutions documented herein.

Community Data Owner		Approved	☐ Yes ☐ No
Signature		Date	/ / 2021
Comments			

Data Collection Sponsor		Approved	☐ Yes ☐ No
Signature		Date	/ / 2021
Comments			