



Northern Territory Aboriginal Health

Key Performance Indicator Information System



Australian Government
Department of Health and Ageing



Northern
Territory
Government

**NORTHERN TERRITORY
ABORIGINAL HEALTH**

KEY PERFORMANCE INDICATORS

(NT AHKPIs)

DATA MANAGEMENT POLICY

and

Data Receiving Protocol

Data Security Protocol

Data Access Protocol

Final Draft

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Policy and Protocol Summary

Introduction

The NT Aboriginal Health Forum (NTAHF) agreed to collect Aboriginal health data for use by Primary Health Care service providers and the NTAHF to enhance strategic, operational and clinical decision-making.

This policy details how the NT AHKPI system and data will be managed, maintained and protected in strict accordance with national and NT information privacy legislation and standards.

Key principles underpinning the policy include:

- That NT AHKPI reports will not contain information enabling the identification of individuals.
- That NT AHKPI data collected is owned by the service provider organisation that sourced the data.
- That each service provider is responsible for the integrity and timeliness of their data, and will have the opportunity to validate and comment on their data prior to finalising reports.

The NT AHKPI System

KPI data is forwarded from each service provider to the secure NT AHKPI data base in the DHF Data Warehouse. All KPI data is subject to strict security and privacy legislative requirements including the National ATSI Health Data Principles, Commonwealth Privacy Act and the NT Information Act. The Data Receiving and Security Protocols detail technical requirements for the delivery and receipt of data into the DHF Data Warehouse, and how the data is kept secure and confidential. The Data Access Protocol details the decision making process and roles and responsibilities to gain access to NT AHKPI data.

Governance of the NT AHKPIs

The chair of the NTAHF is the Data *Collection* Sponsor with overall responsibility for the full-NT-wide data set or collection. This role has been delegated to the KPI Steering Committee (SC) consisting of representatives from the NTAHF partners. The SC has responsibility for considering requests for access to data and reports.

A Technical Working Group and a Clinical Reference Group, each with members from the 3 NTAHF partners, provide advice to the SC on the KPI's, the KPI system and reports.

DHF's Manager of Health Service Data Unit is the NT AHKPI Data Custodian, with day-to-day responsibility for the NT AHKPI data collection.

Each service provider organisation owns the NT AHKPI community level data that they have collected, and has a designated Community Data Sponsor responsible for their data (ie, for their *subset* of the NT AHKPI Data Collection). Each provider organisation will have the opportunity to validate and comment on their community level data prior to finalising the reports.

Access to NT AHKPI Data and Reports

As the sponsors of the community level data, each service provider automatically receives copies of draft (initial release) and final reports for those communities in which they provide services.

Service providers in "mixed model" health centres, who have authorised the on-going release of their data to the other service provider in the health centre, will automatically receive copies of community level reports for health centres in which they jointly operate.

As the Data Collection Sponsor, the NTAHF partner representatives can access copies of de-identified Health Service Delivery Area reports, and will automatically receive NT-wide NT AHKPI reports.

Any HSDA level and NT-wide NT AHKPI reports provided to the designated NTAHF representatives

cannot be shared with any external organisation or group or the public unless there has been prior public release of the data by the NTAHF or agreement to the release by the Steering Committee.

NTAHF partner representatives are responsible for the security and appropriate use of the NT AHKPI data (as defined in this document) within their respective organisations. Access to NT AHKPI data within NTAHF partner organisations will be determined on a 'need to know' basis for the purposes of evidence-based monitoring, planning and policy development.

If a NTAHF partner organisation wishes to release NT AHKPI data or reports to a government body or instrumentality, a NT AHKPI Data Access Approval Form must be completed and submitted to the NT AHKPI Data Custodian.

Policy Objectives

The NT AHKPI Data Management Policy provides a framework for:

- The management, maintenance and expansion of the NT AHKPI system and data.
- Ensuring that NT AHKPI data will be:
 - Protected from unauthorised use
 - Managed in compliance with all national and NT information privacy legislation and standards

Detailed protocols relating to receiving, securing and managing access to NT AHKPI data in the DHF Data Warehouse.

Policy Principles

- NT AHKPI data will contribute to improving Aboriginal health and well-being through:
 - Increased understanding of Aboriginal health and well-being and services issues amongst communities, providers and government.
 - Supporting evidence-based strategic, clinical and operational planning, decision-making and Continual Quality Improvement activities.
- NT AHKPI data will be received, secured, managed and released in strict compliance with national and NT information privacy legislation and standards.
- NT AHKPI data and reports approved for public release, will be aggregated, and will not contain information that will enable the identification of individuals.
- The agreed suite of NT AHKPIs may be expanded or modified to meet emerging information needs, and/or to minimise reporting requirements arising from new national data sets.
- Each service provider has responsibility for ensuring the accuracy, timeliness and integrity of their NT AHKPI data.
- Each service provider, through their designated Community Data Sponsor will be given the opportunity to validate, analyse and comment on draft reports before they are finalised.
- NT AHKPI reports will be prepared in formats that will increase understanding and use by communities, providers and government.

Background

In 2003, the Northern Territory Aboriginal Health Forum (NT AHF) agreed to develop a set of Key Performance Indicators (KPIs) for Aboriginal health¹.

The Department of Health and Ageing (DoHA) and the Department of Health and Families (DHF) funded a project to:

- Finalise validated definitions for an agreed suite of 19 KPIs;
- Develop a KPI system to capture collect, clean, analyse and interpret KPI data within the DHF data warehouse; and
- Develop a KPI reporting system to deliver KPI reports to communities, the NT AHF and to other approved stakeholders.

The project goal was:

“To improve Primary Health Care (PHC) services for Indigenous Australians in the NT by building capacity at the service level and the system level 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”².

The project was completed in 2009. The first round of community-level NT AHKPI reports were distributed to Government and Aboriginal Community Controlled providers in October 2009.

The NT AHKPI System

NT AHKPI data is collected from five data sources across the NT, ie, from four Patient Information Recall Systems (PIRS) (Communicare, PCIS, Medical Director and Ferret), and from an Interim Data Collection Tool (IDCT) that has been developed for use until an electronic PIRS is implemented in all DHF health centres.

The data is kept in the DHF Data Warehouse, which is a repository for securing and storing electronic data from which data and reports can be delivered.

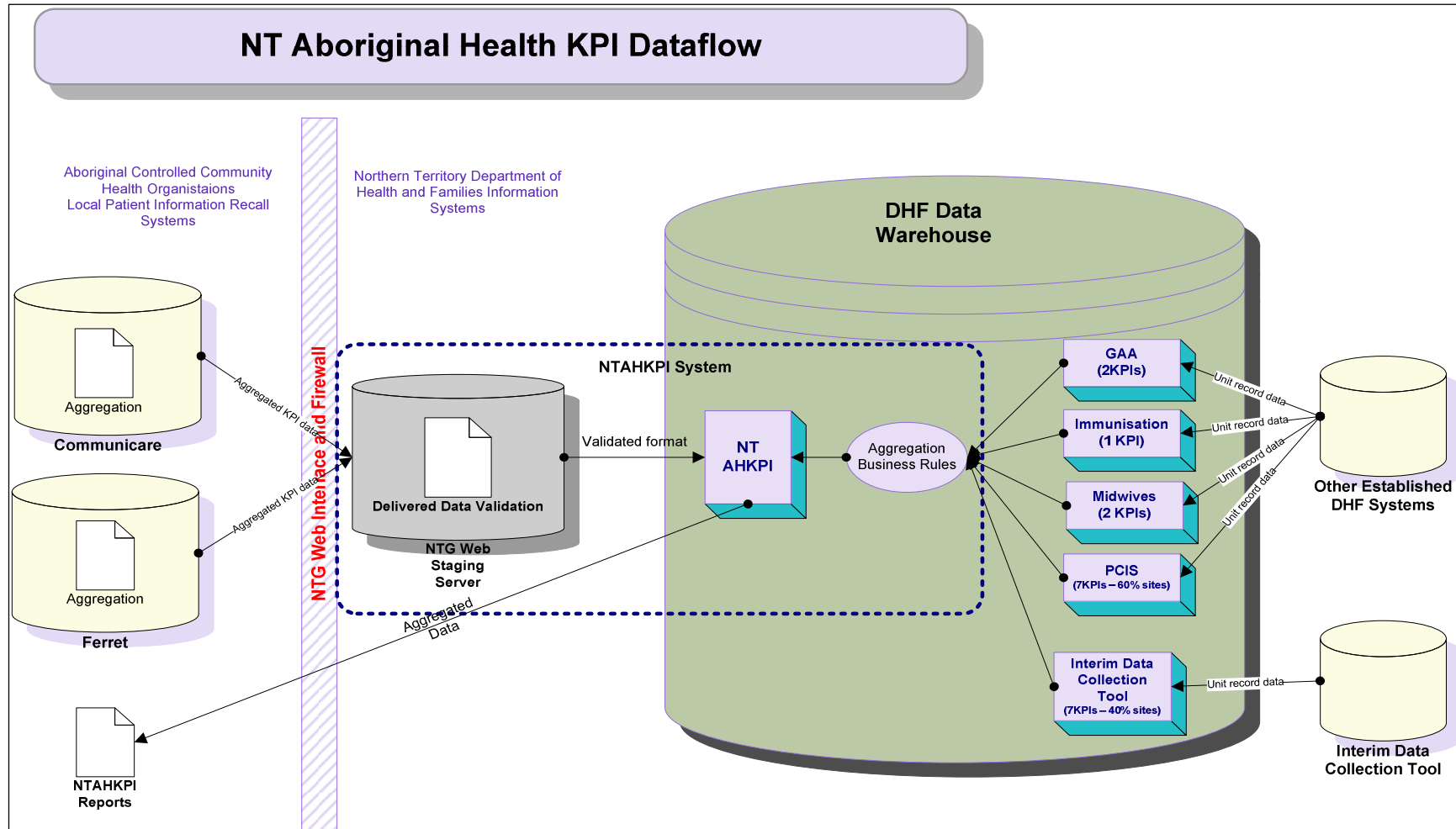
The DHF NT AHKPI team works with the data to analyse and prepare initial release community-level, HSDA and NT-wide reports, which are provided to Community Data Sponsors for comment and further analysis prior to preparing final release reports.

The following page provides an overview of the NT AHKPI system.

¹ The NTAHF consists of senior representatives of the Australian Government's Department of Health and Ageing (DoHA), the NT Department of Health and Families (DHF) and the Aboriginal Medical Services Alliance of the NT. (AMSANT). The Forum oversees Aboriginal health policy and strategy across the NT.

² Project Proposal, 2003, p3

The NT AHKPI System Overview



Definitions

Aggregated Data:

Data collected and reported by organisations as a sum or total over a given time period, for example, monthly or quarterly.

Data Collection:

A store of data captured in an organised way for specific purposes. A collection is not restricted to use by an individual service provider, but is potentially available to a wider group of users. The NT AHKPI data from each service provider forms a data collection within the DHF Data Warehouse.

Community Data Sponsor:

Person within a service provider organisation with a detailed knowledge of individual and community level data, how it is collected, manipulated, extracted and interpreted, and has responsibility for approving release of relevant individual or community level data on behalf of the organisation. Community level data (ie a subset of the NT AHKPI data *collection*) is owned by the health service provider organisation that collects the community level data.

Data Collection Sponsor:

The person ultimately responsible for a data collection. This role can be delegated to a designated position within the organisation which holds the data collection. The Chair of the NT AHF is the NT AHKPI Data Collection Sponsor. This responsibility has been delegated to the NT AHKPI Steering Committee.

Data Collection Custodian:

Person or position with day-to-day responsibility for a data collection on behalf of one or more Data Sponsors, and who physically provides data from a collection when data release is appropriately authorised by the Data Collection Sponsor and/or Community Data Sponsor/s. The Data Custodian receives requests for access to collection data, and is responsible for forwarding such requests to the Data Collection Sponsor and/or Community Data Sponsor for consideration. The Manager, DHF Health Service Data Unit is the Data Custodian for the NT AHKPI data collection.

Data Mart:

A subset of data held in the Data Warehouse for a specific business purpose.

Data Source:

The place from which data is extracted and delivered to a Data Warehouse or System. Data sources can be a Patient Information Recall System (PIRS), a data set provided by internal or external agencies (eg population data sets from ABS), or paper-based collections such as card systems or registers). The main sources for AHKPI data are the PIRS within health service provider organisations ie PCIS, Communicare, Ferret, Medical Director, and the Interim Data Collection Tool which is being used in some NT remote health centres that do not yet have an electronic PIRS.

Data Warehouse:

A secure repository for storing electronic data from which data and reports can be delivered. NT AHKPI data is held in the DHF Data Warehouse.

De-identified Data:

Data from which information that could result in the identification of individuals has been removed. (Eg names, dates of birth etc). Note: The NT AHKPI Data Access Protocol also requires that data and reports that could result in the identification of specific health centres or communities be de-identified. Any requests for NTAHKPI data/reports that could result in identification of individuals or specific communities or health centres will be referred to the relevant Data Owner/s for decision-making.

NT AHKPIs:

A set of Key Performance Indicators (KPIs) used across the NT Aboriginal Primary Health Care system to provide information to support evidence-based planning, decision making and Continual Quality Improvement activities.

NT AHKPI System:

The secure database within the DHF Data Warehouse used to store and manage NT AHKPI data.

Patient Information Recall System (PIRS):

A system used by health service provider organisations to collect, store and generate the patient information necessary to provide services.

Primary Use of Data:

When a health service provider uses personal information collected from a client for the purpose of providing a health service.

Secondary Use of Data:

When a health service provider uses or discloses personal information about an individual for a purpose ("the secondary purpose") other than the primary purpose for collecting it³.

System Administrator:

The person who manages the technical operations of a database system or PIRS for an organisation, as directed by the System Owner.

System Owner:

The person with overall responsibility for managing an operational database or Patient Information Recall System (PIRS) on behalf of the organisation's designated Data Sponsor.

Unit Record Data:

Records relating to the health of an individual.

Governance of the AHKPI System and KPI data**The NT Aboriginal Health Forum (NT AHF)**

The NT AHF comprises senior representatives from the Australian Government Department of Health and Ageing (DoHA), the Aboriginal Medical Services Alliance of the NT (AMSANT), and the NT Department of Health and Families (DHF). The Forum's role is to provide advice and direction on Aboriginal health issues. The NT AHF provided leadership on the development and implementation of the Key Performance Indicators, and the NT AHKPI system.

The Chair of the NT AHF is the Sponsor of the NT AHKPI data collection. This role has been delegated to the NT AHKPI Steering Committee.

Role of the NT AHKPI Steering Committee (SC)

The SC consists of representatives of the three NT AHF partners, and has been delegated the role of NT AHKPI Data Collection Sponsor.

Terms of Reference of the SC

Provide high level advice to the NT AHF with the overall aim of improving the generation and strategic use of NT AHKPI data to improve health outcomes through the Aboriginal PHC system.

³ Refer [Information Act, Information Privacy Principles](#) (IPP 2).

- Advice to the NTAHF to include:
 - Advice on sensitive or critical issues relating to the NT AHKPI system, data and reports and recommended ways forward;
 - Recommended NT AHKPI-related policy and protocols; and
 - Recommendations relating to expansion or improvement of the NT AHKPI system, indicators and reports.
- Maintain and monitor the KPI Issues Register, and refer to the Technical Working Group or Clinical Reference Group as appropriate for their consideration and action or advice.
- Act as the NT AHKPI Data Management Committee by considering, and, where appropriate, approving requests for:
 - Access to KPI data and reports
 - The public release of any reports based on analysis of summary level NT AHKPI data sets aggregated at Health Service Delivery Area (HSDA) or Territory levels.

The NT AHKPI Technical Working Group (TWG)

The TWG reports to the SC, and consists of representatives of each of the NT AHF partners. The role of the TWG is to review the implementation of the NT AHKPIs, and make recommendations to the SC on technical issues that must be addressed in order to ensure that funders, health boards and management can receive timely and accurate reports from data extracted from all Patient Information Recall Systems (PIRS) across the NT.

Terms of Reference of the TWG

This TWG was established to identify and resolve problems that stem from the technical specifications of the IT systems that support the reporting of NT AHKPIs in the first few reporting cycles. It will:

- Review the implementation of the KPIs into Patient Information Record Systems (PIRS) used to record data.
- Review technical problems arising from sending of extracted data from the services PIRS systems to the DHF Data Warehouse.
- Review reports that are returned by DHF to the services as to their relevance, ease of reading by proposed audience, accuracy of data in terms of the statistics generated through PIRS reports, confidentiality of data.
- Make recommendations to SC on PIRS modifications or resource allocation where there are issues with running accurate KPI reports, whether they be due to report parameters, recording of data, incorrectly written reports within the PIRS, training or inability of services to analyse data due to resource or staff shortages
- Develop mechanisms to systematically capture the interpretation and commentary on reports to ensure that local level knowledge and expertise is harnessed to build a body of understanding about the indicators and the issues that are influencing them at the local, regional and jurisdictional levels.
- Report activities and outcomes, and provide recommendations on a 2-monthly basis to the NTAHKPI Steering Committee.

Composition of the TWG

Representatives:

- 1 clinician each from ACCHS and DHF services who report back from the Clinical Reference Group (see below)
- 1 AMSANT PIRS Officer
- 1 CQI coordinator
- 2 IT Business Analysts (1 from ACCHS and 1 from DHF)
- 1 DHF System Analyst
- 1 OATSIH Representative

The NT AHKPI Clinical Reference Group (CRG)

The CRG reports to the Steering Committee (SC), and consists of representatives of each of the NT AHF partners. Its role is to review the results of the NT AHKPIs for their clinical relevance, and as a tool in clinical CQI activities, and make recommendations to the SC on changes needed to ensure that the NT AHKPIs provide the required feedback to clinicians, funders, health boards and management.

Terms of Reference of the CRG

- Review the parameters of the KPIs as to their accuracy in obtaining the data required. This would include the clinicians assessing whether the KPIs capture the correct clinical indicators and are able to be used to improve clinical outcomes.
- Recommend modifications to KPI definitions.
- Recommend approaches to using KPI data, including changes to health practice and clinical guidelines.
- Forward issues or recommendations to the CQI Planning Committee based on the data outcomes- especially those issues that are evident across the service system
- Review the impact of KPI data collection on clinical and administrative processes, and identify good practice or lessons learnt that can be shared across the PHC service sector or promoted through CQI activities.
- Review the format of the Community-level reports as to their relevance, ease of reading by proposed audience, and accuracy and confidentiality of data
- Recommend PIRS modifications or resource allocation where there are issues with running accurate KPI reports, whether they be due to report parameters, recording of data, incorrectly written reports within the PIRS, training or inability of services to analyse data due to resource or staff shortages
- Report activities and outcomes, and provide recommendations on a 2-monthly basis to the NTAHKPI SC
- Monitor national Performance Indicator development and recommend modifications to, or new KPIs, based on these Indicator developments.
- Liaise with relevant Clinical Working Groups to ensure that issues arising are addressed in the NT AHKPI data set. (eg WHO Growth Chart Committee, the Under 5 Working Group)

Composition of the CRG

Representatives:

- 1 Senior PH Clinician each from ACCHS and DHF services
- 3 Clinicians each from the ACCHS sector and DHF
- 1 AMSANT PIRS Officer
- 1 CQI Coordinator
- 2 IT Business Analysts (1 from ACCHS and 1 from DHF)
- 1 DHF System Analyst
- 1 OATSIH Representative

Role of Health Service Provider Organisations

All NT AHKPI data collected by Government and Community Controlled health service providers are the property of the organisation that collected the data. The community level data that is owned by the service provider is a *sub-set* of the secure NT AHKPI data *collection*.

The Chief Executive Officer of each organisation is the Community Data Sponsor for their sub-set of the NT AHKPI data collection, and is responsible the collection, management, security, use and release of their data. This role is usually delegated by the CEO to a person who is designated as the Community Data Sponsor for the organisation. The Community Data Sponsor is the point of contact within the organisation for the NT AHKPI Data Collection Custodian, ie, Manager, DHF Health Services Data Unit.

Each health service provider organisation is responsible for ensuring the integrity, accuracy and completeness of their data and reports. This will require them to establish clear internal protocols for reviewing, interpreting and approving draft reports.

Service providers will have the opportunity to validate and comment on their community level data prior to finalising reports.

Health service providers also have the opportunity to use NT AHKPI data and reports to:

- Engage with communities and health boards on health and well-being issues;
- Inform understanding of trends in individual and population health;
- Identify factors influencing these trends; and
- Inform appropriate action, planning and policy development, including local level Continual Quality Improvement activities.

Requests to access NT AHKPI data and reports from the DHF Data Warehouse that could potentially result in the identification of individuals, or specific health centres or communities will always be referred to the relevant Community Data Sponsor for decision-making.

Requests to access NT AHKPI data and reports from the DHF Data Warehouse, aggregated and de-identified at the Health Service Delivery Area and NT-wide levels, must be approved by the NT AHKPI Steering Committee, on behalf of the Health Service Provider organisation/s.

NT AHKPI Data Receiving Protocol

The NT AHKPI Data Management Policy is supported by the Data Receiving Protocol.

There are five Patient Information Recall Systems (PIRS) currently used to collect Aboriginal KPI data in the NT. (ie PCIS, Communicare, Medical Director, Ferret and the Interim Data Collection Tool - IDCT).

Data from each PIRS must be delivered in a consistent technical format in order for the system to work, and for meaningful reports to be generated.

The "Northern Territory Aboriginal Health Key Performance Indicator Data Receiving Protocol" is a separate document developed by the NT AHKPI Technical Working Group, and approved by the NT AHF in July 2009. The technical aspects of delivering and receiving the KPI data into the NT AHKPI system in the DHF Data Warehouse are controlled in accordance with this protocol.

The Data Receiving Protocol details the technical requirements in the following areas: KPI references, data receiving business rules, code tables, and data segments.

It can be found on the NT AHKPI website in the system documents section:

www.nt.gov.au/health/ahkpi

NT AHKPI Data Security Protocol

The NT AHKPI Data Management Policy is supported by this Data Security Protocol.

Policy Principle:

NT AHKPI data will be received, secured, managed and released in strict compliance with national and NT information privacy legislation and standards.

Legislation and Standards

This protocol describes the security systems in place to control access to data held in the DHF Data Warehouse.

These security systems within the NT Government and DHF information systems architecture have been designed to comply with *Australian Standard A/NZS ISO/IEC 17799:2001 Information Technology – Code of practice for information security management*, and with the following national and NT information management and security legislation and standards:

- Commonwealth Privacy Act 1988.
- The NT Information Act 2002.
- National Aboriginal and Torres Strait Islander Health Data Principles 2006.
- The Cultural Respect Framework for Aboriginal and Torres Strait Islander Health 2004-2009, AHMAC 2004.
- Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research, NHMRC 2003.
- Guidelines for Commonwealth Information Published in Electronic Formats, AusInfo, 1999.
- DHF Data Access Protocol for Secondary Use of Data Warehouse Derived Data Collections, February 2009.

Physical Security

All DHF premises are physically secured against unauthorised access. Entry is monitored by electronically controlled access systems activated by individually coded access cards. All visitors are signed in by a staff member and accompanied whilst in the building.

The Data Warehouse and data marts are held on a server located in the Server Room at Royal Darwin Hospital. The server room has a security-coded lock. The code is provided to IT Support Staff only.

Security processes apply to all personal computers. A screen locking mechanism on all desktop monitors prevents accidentally revealing data to unauthorised persons, or tampering and illegal data access whilst the machine is unattended.

NT Government Network

DHF's Internet gateway/firewall security is managed by the Northern Territory Department of Business and Employment in accordance with relevant national and NT information privacy legislation.

Local Area Network

Access to the DHF Local Area Network (LAN) requires valid user IDs and passwords. LAN passwords expire after 30 days and network usage and access is closely monitored.

Database Management System

The DHF Data Warehouse and the NT AHKPI system are built and maintained using the Oracle 10g database management system. To access NT AHKPI data, users must be registered with Oracle, and their assigned group determines their level of access. Data Warehouse staff are the only users who

have access to all data in the Warehouse.

DHF Information Division Staff

Access to Data Warehouse data is granted only when required by a staff member to carry out their duties. Access to all DHF Data Warehouse data sets must be approved by the relevant Data Custodian, in accordance with DHF Data Access Protocols. A record is kept of all instances of access to DHF information systems, and these records are regularly reviewed to ensure security protocols are followed.

Business Objects Reporting Application

BusinessObjects users have no direct access to the data in the Data Warehouse or data marts stored on the Data Warehouse servers. Their access to data is via the DHF Intranet site, and they require a user name and password that determines the functionality available to them when using BusinessObjects, and the information.

NT AHKPI Data Access Protocol⁴

The NT AHKPI Data Management Policy is supported by this Data Access Protocol.

This Data Access Protocol (DAP) 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 providing access to identifiable NT AHKPI information about individuals, specific communities or specific health centres.
2. Facilitate access to aggregated and de-identified NT AHKPI data to assist in evidence-based service monitoring, planning, decision-making and Continual Quality Improvement activities.

Access to potentially identifiable data

Identified 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 by which individuals, specific communities or specific health centres might be identified will only be provided with the authority of the appropriate Community Data Sponsor (ie within the relevant Government or ACCHO health organisation). Each health service provider may also choose to seek endorsement for the release of the data from their community/s.

Access to Aggregated NT AHKPI Data by Health Service Provider Organisations

Service providers are able to access their own data held in the DHF Data Warehouse via the password protected web-based information system. This enables them to check the accuracy of their data, make corrections where necessary, and ensure that any interpretation or comment is accurate and up-to-date.

Each service provider will nominate staff who will be able to access the web-based information system and either view, update or approve data for their service.

The NT AHKPI Helpdesk (ahkpi.communications@nt.gov.au) will manage overall access and privileges for the web based system via user IDs and passwords.

Access to KPI aggregated data reports by NT AHF partner organisations.

As the founding Data Collection Sponsor, the NTAHF partner representatives can access copies of de-identified Health Service Delivery Area 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 the designated NTAHF representatives cannot be shared with any external organisation or group or the public unless there has been prior public release of the data by the NTAHF or agreement to the release by the Steering Committee.

NTAHF partner representative are responsible for the security and appropriate use of the NT AHKPI data (refer "Background") within their respective organisations. Access to NT AHKPI data within NTAHF 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 Steering Committee (SC) and, if necessary a Data Access Approval Request form should be completed and forwarded to the SC for consideration.

⁴ Note: This protocol only deals with access to NT AHKPI data in the DHF Data Warehouse. It does not deal with access to NT AHKPI data stored in each service provider's PIRS.

NT-level KPI reports will be automatically generated twice per annum from the NT AHKPI system, and delivered directly to the NTAHF via the NTAHF secretariat. Consistent with the agreed original goal of the NT AHKPI project, these aggregated, de-identified reports will be used by the NTAHF partners only for service monitoring, planning, decision-making and Continual Quality Improvement purposes. (Refer p4 - Background)

If a NTAHF partner organisation wishes to release NT AHKPI data or reports to another government body or instrumentality, a NT AHKPI Data Access Request Form must be completed and submitted to the NT AHKPI Data Custodian.

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

Access to NT AHKPI aggregated data in “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 their organisation has been documented, the designated Community Data Sponsor for both organisations will automatically receive NT AHKPI aggregated data reports for that health centre/community. The on-going 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 are auspicing 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.

Access to NT AHKPI aggregated data reports to other organisations or individuals

Any individuals, organisations or research teams seeking access to aggregated NT AHKPI data or reports will be required to complete the NT AHKPI Data Access Request form. The form will require them to outline how the data will be used to support:

- Increased understanding of Aboriginal health and well-being and services issues.
- Evidence-based strategic, clinical and operational planning, decision-making and Continual Quality Improvement activities.

The completed NT AHKPI Data Access Request Form must be accompanied by a copy of the research proposal, and, where available, 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, including evidence of ethics approval from the most relevant research ethics committee; or
- Forward the request to the designated Community Data Sponsor for the service provider (where the privacy of individuals and specific communities or health centres may be compromised); or
- Forward the request to Chair of the NT AHKPI Steering Committee, along with recommendations.

The Steering Committee will decide whether to authorise the data request, based on an assessment of whether or not the proposed project will contribute to the attainment of the agreed goals of the NT AHKPI data collection.

Access to NT AHKPI data and reports for research purposes

The completed NT AHKPI Data Access Request Form must be accompanied by a copy of the research proposal, and, where available, evidence of ethics approval, and submitted to the NT AHKPI Data Custodian. The full set of documentation will be forwarded to the NT AHKPI Steering Committee. The Steering Committee will decide whether to authorise the data request, based on an assessment of whether or not the proposed project will contribute to the attainment of the agreed goals of the NT AHKPI data collection. In order to minimise delay, the Steering Committee may give conditional approval to release data, pending approval by the relevant ethics committee.

Access to data/reports by the DHF NT AHKPI system management team

The NT AHKPI Data Custodian (DHF Manager, Health Services Data Unit) will be responsible for facilitating access to data or reports authorised by the NT AHKPI Data Collection Sponsor (NT AHKPI Steering Committee) or by Community Data Sponsor/s. All DHF staff sign an undertaking of confidentiality, and only staff involved with the system will have access to the data through the NT AHKPI Data Custodian.

When data/ release is approved

Authorised data recipients must sign and submit an “Undertaking” form to the NT AHKPI Data Custodian before the information is released.

Reports on the NT AHKPI that have been formally released to the public will be made available on the NT AHKPI website.

Please find at Appendix One, a Data Access Approval Flow Chart that summarises the approval process.

Management of Approved Data Access Requests within DHF

The DHF NT AHKPI Data Custodian will only deliver NT AHKPI data to Authorised Users. The Data Custodian is the primary contact for those seeking access to NT AHKPI data stored in the DHF Data Warehouse.

A request for delivery of NT AHKPI data stored in the Data Warehouse is to be lodged with the Data Custodian using the Request for Data Access Request form (as at Appendix Two). This form is available on the NT AHKPI website: www.nt.gov.au/health/ahkpi

Based on information provided on this form, the DHF NT AHKPI Data Custodian will:

- Consider whether the reasons for requesting the NT AHKPI data satisfy Information Privacy Principles;
- Verify that the requested NT AHKPI data is held in the Data Warehouse, and provide feedback to the applicant on NT AHKPI data quality and date range availability;
- Verify that any proposed research using the data has been approved by a Human Research Ethics Committee;
- Ensure that appropriate approval has been given by the relevant service provider Community Data Sponsor or by the NT AHKPI Steering Committee as the Data Collection Sponsor;
- Provide advice to the health service provider Community Data Sponsor/s or the NT AHKPI Steering Committee on whether the request should be approved.

According to the nature of the request, Community Data Sponsors may impose restrictions on access to their organisation's NT AHKPI data, or may specify alternate arrangements for the delegation of approval.

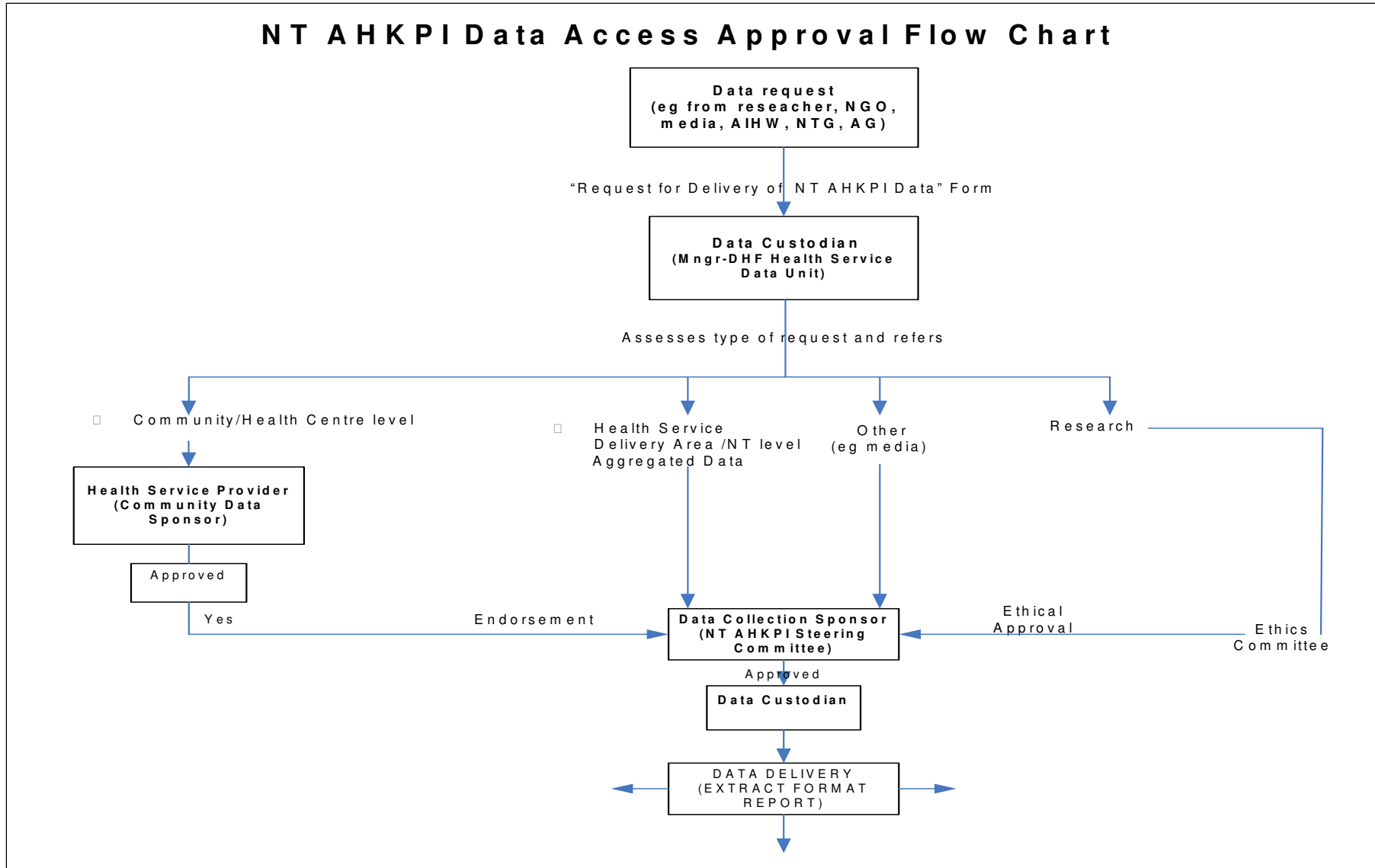
The client is required to agree that, prior to any publication of NT AHKPI data, the Community or Collection Data Sponsor/s will be given the opportunity to review and comment on NT AHKPI data interpretations, and that these comments will be included in the report.

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 Sponsor/s have the right to refuse permission to publish their organisation's data or reports.

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

DHF is responsible for extraction, formatting and delivery of the data or report. An activity log of Authorised Users accessing NT AHKPI data from the Data Warehouse will be reported to the NT AHF annually.

Appendix One: Data access approval flow chart



Appendix Two: Request for Delivery of NT AHKPI Data from the DHF Data Warehouse Form

(Available on NT AHKPI Website:
www.nt.gov.au/health/ahkpi)

REQUEST FOR DELIVERY OF NT AHKPI DATA FROM THE DHF DATA WAREHOUSE

This application should be forwarded to Information Division, DHF. You will be contacted by the NT AHKPI Data Custodian who will discuss the level of authorisation that will be required, and any additional Information that must be provided before the application can be processed. Further info: DHF NT AHKPI Data Custodian (ahkpi.communications@nt.gov.au).

PART A: APPLICANT DETAILS

Date of Request:
Name of applicant:
Organisation:
Telephone:
Email:
Manager's Name, Position:
Manager's Signature/Endorsement and comments:

Applicant certification about use of information

The information sought will be used solely for the purpose of undertaking this project/activity. All reasonable measures will be taken to ensure that the arrangements for the security and use of the information accessed are complied with. 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 Sponsor) or health service provider Community Data Sponsor/s. Where the approval of the Data Collection Sponsor or health service provider Community Data Sponsor/s is given for the release of data or information, adequate opportunity for review and comment will be provided.

Signature of Applicant:

PART B – DATA REQUEST DETAILS (Attach separate sheets as necessary)

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.

Overview of Project/Activity (Project aim, cooperating agencies, sponsors, stakeholders, funding sources and approvals, including ethics approvals)

Objectives of the Project/Activity (the reasons for the data request, including any legislative requirements authorising collection of the data, and the purposes for which it will be used)

General description of data requested:

Data elements requested:

Data range/s requested: (e.g. service events date range, age range.)

Data request category: Ad hoc report/periodic report/data audit

Requested delivery time: This week/this month/next month/this quarter/next six months

Level of request: Urgent/important/routine

Period of approval: Ongoing or fixed period – the latter is required for a project

PART C – APPROVALS

I have read this application and provide the following comments or decisions.

1. **Data Custodian:** Date, comments, recommendations and referrals

2. **Data Collection Sponsor and/or Community Data Sponsor/s** as required)

Date _____ Name _____ Designation _____

Approved /Not Approved

Comments:

Signature:

Date _____ Name _____ Designation _____

Approved /Not Approved

Comments:

Signature:

Date _____ Name _____ Designation _____

Comments:

Signature:

Appendix Three: Document Control

Vers	Date	Made by	Status Distribution/	Major changes from previous version	Major comments received on this version
1.1.2	15/10/07	Richard Inglis	Endorsed by NTAHF for trial. To partners. for trial.	<ul style="list-style-type: none"> Incorporated draft Data Receiving and Data Access protocols 	<ul style="list-style-type: none"> Document complex /hard to understand. Need "Plain English" summary. Lack of clarity re ownership of data. Lack of clarity re approval process to release data.
2.1 Feb 2010	26/2/10	Sally Matthews	To SC for comment.	<ul style="list-style-type: none"> Reflect completion of the system and new governance structure. Attempt to clarify issues about ownership of service v collection data. Inclusion of principles. 	<ul style="list-style-type: none"> Need for consistent description of roles of governance structure bodies Need Plain English summary. Need separate section on access to data in dual provider health centres. Need to clarify role of Data Sponsor
2.2 Mar 2010		Sally Matthews	To SC for comment.	<ul style="list-style-type: none"> More consistency in description of governance groups Inclusion of summary Dual provider health centres. 	<ul style="list-style-type: none"> Concerns re "Data Owner" and privacy of organisations or communities. Need to consider original aims of the NT AHKPI collection and protect rights or data owners who may choose to withdraw support for the system if they feel the data is not used in accordance with original goals. Individual service providers must give approval to release data when their service or specific communities might be identified. (p14) SC would not be assessing validity of proposed research, but would be assessing its relevance to the goals

Vers	Date	Made by	Status Distribution/	Major changes from previous version	Major comments received on this version
					<p>of the NT AHKPI system.</p> <ul style="list-style-type: none"> • SC could provide conditional approval to release data pending final approval when ethics approval gained. • NTAHF partners should not be able to distribute HSDA level reports internally. • Auspicing agencies needed to follow up internally to ensure they were authorised to automatically receive reports in mixed model health centres. • Need document control.
2.3 April 2010		Sally Matthews	To SC for comment.	<ul style="list-style-type: none"> • NTAHF partner reps automatically receive copies of NT wide reports only. Can request HSDA level reports. (p19-20) • Simplification of Terms of Reference of Technical Working Group. • Organisations auspicing services in mixed model health centres to follow up internally to ensure correct authorisation. (p20) • SC can give approval to access data conditional upon evidence being received of ethics approval. (P21) • Document control section added. 	<ul style="list-style-type: none"> • OATSIH unable to support this version due to need for access to data as specified in Funding Agreements with service providers. • Agreed that different NTAHF forum partners have different needs for KPI data • Each Forum partner is also subject to information privacy requirements. • Agreed that OATSIH would review relevant sections for final consideration by SC. • Agreed that the NTAHF paper on the final version would specifically mention the issues of partner access to HSDA and NT wide reports when seeking approval.
2.3 April 2010		Rachel McGahey OATSIH	To Chair of SC	<ul style="list-style-type: none"> • Suggested changes to access by NTAHF partner agencies. 	

Vers	Date	Made by	Status Distribution/	Major changes from previous version	Major comments received on this version
2.4 July 2010		Richard Inglis	To SC chair and OATSIH for review.	<ul style="list-style-type: none"> • Clear alternative term for “Data Owner”. Made the distinction between repository versus community ‘data ownership’ by describing a ‘Data Collection Sponsor’ and ‘Community Data Sponsor’. Thus avoiding the use of ‘data owner’ terms - as the “owner” of data is the individual client. 	<ul style="list-style-type: none"> • Steering Committee required a clear alternative term for “Data owner.”
2.4 July 2010	20/7/10	Sally Matthews	To SC meeting of July 2010	<ul style="list-style-type: none"> • Reviewed and consolidated input from OATSIH and DHF into version 2.4. • Some editing throughout to ensure consistent use of terms ie Community Data Sponsor, and Data Collection Sponsor. • Updated Appendix 1: Data Access Approval Flow Chart to reflect agreed terminology • Simplified Data Access Request Form • Document control section updated. 	<p>Steering committee mtg postponed. Comments received from Dr Liz Moore, AMSANT as follows:</p> <p>6/8/10 Some ambiguity in the data protocol about what access NTAHF partner organisations have to the data. On page 20 it says that if they want anything more than six monthly HSDA reports and NT wide reports, they have to fill out a data request form (and thus be considered by the steering committee). On page 22 it says that a request from a NTAHF partner organisation can not be refused but the health service provider may not refuse it but may ask the 19 KPI SC to attach a note of concern to the data. This is ambiguous . I think this paragraph on page 22 could just be removed . It would be good if it was clear before going to NTAHF.</p> <p>9/8I bolded the two paragraphs, the one I would take out is on page 23 (not page 22). As it is redundant I think and gives the impression that partner organisations can request any data they like whereas earlier</p>

Vers	Date	Made by	Status Distribution/	Major changes from previous version	Major comments received on this version
					it is clear that they get NT wide and HSDA reports six monthly (and? Regional data) and need to request any additional data from the SC
2.5	9/8/2010	Sally Matthews	To SC meeting of August 2010 along with draft covering memo to the NTAHF	<ul style="list-style-type: none"> Removed the following paragraph from p22 "Where NT AHKPI data is to be released within the NT AHF partner organisations, health service provider Data Sponsor/s may not refuse the release, but may seek approval from the NT AHKPI Steering Committee to include a note of concern or interpretation if the provider decides this is appropriate for their data." Added the following sentence to last paragraph on p 21. "and that these comments will be included in the report." 	<p>Draft 2.5 discussed at SC meeting of 25/8/2010. Agreed</p> <ul style="list-style-type: none"> to add "de-identified" before HSDA reports under section headed "Access to KPI aggregated data reports by NT AHF partner organisations." change to order of sections.
2.6	26/8/10	Sally Matthews		<ul style="list-style-type: none"> Made changes in accordance with SC meeting of August 25th, 2010. Also amended summary of policy section accordingly. 	