QAIHC

Queensland Aboriginal and Islander Health Council

Data Governance Protocols

Version 6.0

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Document Control

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5.0	30/09/2018	Amy Dellit & Anna Sheahan	Updated document to include Notifiable Data Breaches Scheme and Data Request Form
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Acronyms

AHMAC	Australian Health Ministers Advisory Council
ATSICCHS	Aboriginal and Torres Strait Islander Community Controlled Health Service
APCC	Australian Primary Care Collaborative
APP	Australian Privacy Principles
CAT4	Clinical Audit Tool
CQI	Continuous Quality Improvement
EMR	Electronic Medical Record
GIS	Geographic Information Systems
HIT	Health Information Team, QAIHC
HREOC	Human Rights and Equal Opportunity Commission
IAHP	Indigenous Australian Health Program
ICT	Information, Communication and Technology
IF	Improvement Foundation
IPPs	Information Privacy Principles
LCG	Lead Clinician Group
MBS	Medicare Benefits Schedule
NDB	Notifiable Data Breaches scheme
NHMRC	National Health and Medical Research Council
nKPIs	National Key Performance Indicators
OCHREStreams	Online Community Health Reporting Environment
OSR	Online Services Report (previously Service Activity Reporting)
PATCAT	Practice Aggregation Tool for the Clinical Audit Tool
PDSA Cycles	Plan, Do, Study, Act Cycles
PenCS	Pen Computer Systems
PIRS	Patient Information Record System
QAIHC	Queensland Aboriginal and Islander Health Council
RACGP	Royal Australian College of General Practitioners
RAICCHO	Regional Aboriginal and Islander Community Controlled Health Organisation
SPPs	State Privacy Principles
TORPEDO	Treatment of Cardiovascular Risk in Primary Care using Electronic Decision Support

Introduction

This document establishes standards and processes for the secure collection, storage and release of information by the Queensland Aboriginal and Islander Health Council (QAIHC) on behalf of its Member services (see Appendix 1 for map of QAIHC Member Services). These protocols are intended to supplement National and Queensland State policies, protocols and guidelines associated with the management of health information. These protocols are designed to restrict access to the data held at QAIHC to protect the ownership of the data and privacy of individual services, clients and organisations. The Health Information Team (HIT), and its associated Manager and General Manager, are the responsible party for the data custodianship and appropriate policies for the management of this health information within QAIHC.

This document identifies guiding principles and health information standards and processes throughout the QAIHC data process flow and life cycle:

1. Creation and Collection of Data
2. Data Storage and Access
3. Data Quality and Analysis
4. Publication and Release of Data
5. Health Information Team (HIT) Data Products and Outputs
6. Data Retention and Disposal
7. Communication and Collaboration for Continuous Quality Improvement (CQI) and Data Support
8. Future Directions and Management of Data

Background

Queensland Aboriginal and Torres Strait Islander Community Controlled Health Services (ATSICCHS) and QAIHC have recognised the need to build the evidence base to support increased and continued investment within the ATSICCHS sector in Queensland. The role and functions of the HIT are to:

1. Inform and be guided by the QAIHC Board and Management
2. Establish and maintain Stakeholder Relationships
3. Establish and maintain enabling Technology Infrastructure
4. Develop Health Information Evidence Base
5. Encourage, support and build capacity for all data related activities in RAICCHOs and ATSICCHSs
6. Undertake Development Activities to advance the above 5 functions.

Data informs planning, policy and advocacy, for service delivery, clinical quality improvement and contributes to the evidence base for decision making. QAIHC has a responsibility to its Member Services to implement procedures to address all aspects of data protection and good practice in the management of health and health-related information about Aboriginal and Torres Strait Islander peoples in Queensland.

Parties to these Protocols

The parties to the QAIHC Data Governance Protocols are Members of QAIHC (see Appendix 1) and, when necessary, Regional Aboriginal and Islander Community Controlled Health Organisations (RAICCHOs). These protocols form the basis of local partnership data agreements between the ATSICCHS in Queensland and QAIHC. Any agreements developed locally regarding the collection and use of health and health-related information about Aboriginal and Torres Strait Islander peoples should be consistent with the principles outlined in these Protocols.

Guiding Principles

QAIHC must comply with the Commonwealth Privacy Act, 1988[1] and the Australian Government Agencies Privacy Code (the Code). The Australian Privacy Principles (APPs)[2], the Notifiable Data Breaches (NDB)[3] scheme and the Health Information and Medical Research provisions are contained within the Privacy Act. Australian Privacy Principles (APPs) replaced the Information Privacy Principles (IPPs) and National Privacy Principles (NPPs) as of 12th March 2014. The APPs govern the conduct of Commonwealth agencies and private organisations in their collection, management, use and disclosure of records containing personal information.

As of 22nd February 2018, the NDB scheme was established. The scheme is under Part IIIC of the Privacy Act 1988 and requires entities to respond to data breaches, including QAIHC. Entities have obligations to notify when a data breach is likely to cause serious harm to an individual. QAIHC also abides by the Queensland Government Information Privacy Act 2009[4] and ensures all work complies with this legislation.

QAIHC works with third parties in the collation and analysis of Member Service data. These third parties must also comply with the Privacy Act and have their Privacy Policies and Data Breach Response Plan freely available on their websites. In April 2022, PenCS released a *Data Governance Framework – Guiding Principles*[5] update document which outlines their ethical framework and principles in working with data.

QAIHC HIT is guided by the Maiam nayri Wingara Indigenous Data Sovereignty Collective and the Australian Indigenous Governance Institute Data Sovereignty Principles. QAIHC recognises and upholds principles of Indigenous Data Sovereignty and in particular those developed at the national Indigenous Data Sovereignty Summit in 2018 which outlined that Australian Indigenous people have the right to:

- Exercise control of the data ecosystem including creation, development, stewardship, analysis, dissemination and infrastructure.
- Data that is contextual and disaggregated (available and accessible at individual, community and First Nations levels).
- Data that is relevant and empowers sustainable self-determination and effective self-governance.
- Data structures that are accountable to Indigenous peoples and First Nations.
- Data that is protective and respects our individual and collective interests.[6]

Strict data sovereignty is important to the integrity of our relationship with our Member Services. QAIHC HIT has implemented procedures and a data consent form to ensure Member Service remain

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[1] Australian Government (1988) The Privacy Act https://www.legislation.gov.au/Series/C2004A03712

[2] Office of the Australian Information Commissioner (2018) *Australian Privacy Principles* https://www.oaic.gov.au/privacy-law/privacy-act/australian-privacy-principles

[3] Office of the Australian Information Commissioner (2018) *Notifiable Data Breaches Scheme* https://www.oaic.gov.au/privacy-law/privacy-act/notifiable-data-breaches-scheme

[4] Office of the Information Commissioner Queensland (2009) *Queensland Government Information Privacy Act* https://www.legislation.qld.gov.au/legisltn/current/i/infopriva09.pdf

[5] PenCS (2022) Data Governance Framework – Guiding Principles https://www.pencs.com.au/about-us/governance/

[6] University of Melbourne (2017, 11-12 October 2017). Indigenous Data Sovereignty Symposium presentations and roundtables. Paper presented at the Indigenous Data Sovereignty Symposium, Melbourne.

in control of how, where and who views and receives their data. As data custodians of Member's data, we always ensure that the release of data meets the priorities and strategic alignment of Member's and QAIHC and is beneficial to the Aboriginal and Torres Strait Islander community.

QAIHC is also guided by the QAIHC Data Governance Protocols (Box 1) are adopted from the guiding principles identified in the *NSW Aboriginal Health Information Guidelines (1998)*[7] and the *AIHW, for the Australian Health Ministers Advisory Council: National Aboriginal and Torres Strait Islander Health Data Principles*[8] (Appendix 3).

QAIHC recognises and takes into account the principles outlined by the RACGP[9], NHMRC[10,11,12], NACCHO[13] and HREOC[14].

[7] **Minister for Health of the State of New South Wales, The New South Wales Department of Health and The New South Wales Aboriginal Health Resource Cooperative Limited (1998)** ***NSW Aboriginal Health Information Guidelines.*** http://www.ahmrc.org.au/index.php?option=com_docman&task=doc_download&gid=15

[8] Australian Health Ministers Advisory Council (2006) *National Aboriginal and Torres Strait Islander Health Data Principles.* AIHW Canberra. http://www.aihw.gov.au/nagatsihid/

[9] General Practice Data Governance Council (2011) *Data use within the context of secondary use of data from general practice.* Royal Australian College of General Practitioners. Melbourne. http://www.gpdgc.org.au/documents/GPDGC_Data_UsePrinciple_Paper.pdf

[10] NHMRC (2003) *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/e52.pdf

[11] NHMRC (2006) *Keeping Research on Track: A Guide for Aboriginal and Torres Strait Islander peoples about health research ethics* http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/e65.pdf

[12] NHMRC (2010) *The NHMRC Road Map II: A strategic framework for improving the health of Aboriginal and Torres Strait Islander people through research.*

[13] National Aboriginal Community Controlled Health Organisation (1997) *National Data Protocols for the Routine Collection of Standardised Data on Aboriginal and Torres Strait Islander Health*

[14] Human Rights and Equal Opportunity Commission (1998) *Minding Your Own Business. Privacy protocol for Commonwealth agencies in the Northern Territory handling personal information of Aboriginal and Torres Strait Islander people* *http://www.privacy.gov.au/materials/types/guidelines*

Box 1. Guiding Principles of QAIHC Data Governance Protocols

Principle 1	The management of health and health-related information about Aboriginal and Torres Strait Islander peoples must be ethical, transparent, meaningful and useful to Aboriginal and Torres Strait Islander peoples. Such determinations may be made at State or local level, as appropriate.
Principle 2	Information about the health of Aboriginal and Torres Strait Islander peoples and the services they receive must be used to support improved health outcomes for Aboriginal and Torres Strait Islander peoples and better planning and delivery of health services.
Principle 3	The analysis, interpretation and reporting of Aboriginal and Torres Strait Islander health and health-related information should occur collaboratively between the parties as per the QAIHC Data Governance Protocols.
Principle 4	The privacy and confidentiality of Aboriginal and Torres Strait Islander peoples and health service providers must be protected in accordance with all other legislation or guidelines pertaining to the sector.
Principle 5	Health service providers should inform Aboriginal and Torres Strait Islander peoples about how and why their health and health-related information is collected and used and what to do in the event of a data breach. Health service providers must obtain the informed consent of the Aboriginal and Torres Strait Islander peoples for such use of their health and health-related information and give them the opportunity to refuse consent.
Principle 6	While health service providers have common information needs, there is also diversity among them which generates unique information requirements.

Ownership and Custodianship of Information

ATSICCHS are recognised as the owners of any data submitted to the QAIHC. As data custodian, QAIHC HIT acknowledges the need to strictly adhere to its privacy and confidentiality obligations, to maintain integrity of, and respect, the data and the members we represent. Data submitting Member services and QAIHC are bound by legal deeds (data agreements) which outline the terms of how the data received and stored by QAIHC is kept confidential and secure. The QAIHC Data Deeds describe the services QAIHC HIT will provide to data submitting services and also include an additional consent form for Member Services to indicate which other QAIHC staff may access their data if required. QAIHC has a responsibility to its member services and regional entities to protect and manage data according to best practice. In relation to identifiable data, this includes ensuring that:

- identifiable information is not released publicly,
- identifiable information cannot be derived from disseminated data,
- identifiable data is collected in a manner that ensures it remains secure and confidential,
- data is maintained and accessed securely,
- individuals are notified of a data breach if there is a likelihood of serious harm.

Custodianship of personal information involves responsibilities including:

- ensuring the information records are stored in a secure physical environment to prevent unauthorised access, destruction, use, modification or disclosure,
- maintaining the quality and accuracy of the information record,
- being transparent and accountable throughout the data process flow and life cycle and management of personal information,
- determining when and where information disclosure and utilisation are appropriate, in accordance with the principles and terms of these Protocols,
- determining when and where information disclosure and utilisation are appropriate, in accordance with the QAIHC Health Information Data Services Deeds,
- notifying its members and individuals who are impacted by any data breaches as required by the NDB scheme,
- maintaining a data breach response plan and ensuring that any possible data breaches are handled appropriately.

ATSICCHS who are custodians of information records about Aboriginal and Torres Strait Islander peoples share these responsibilities and as such should have their own Privacy Policies outlined and reviewed on their websites for the public to access. ATSICCHS also must comply with the Commonwealth Privacy Act and other regulatory provisions as mentioned above.

To ensure it meets its custodianship obligations, QAIHC must comply with the following requirements:

- QAIHC staff who, in the course of performing their duties, are required to sign a contract of employment which section 15 outlines a confidentiality agreement between the employee and QAIHC pertaining to all information which may be accessed while working at QAIHC.
- All work performed by consultants, contractors, seconded staff, visiting fellows and students that involves access to health information and other information held in the QAIHC Data Repository, must be authorised by written contracts that impose information security and privacy obligations in line with these protocols.
- QAIHC must maintain secure server environments and IT systems for data storage.

Access to data sets at QAIHC

Datasets accessed at QAIHC contain aggregated and de-identified information of patients whom have attended an ATSICCHS, as well as subsets of information on survey populations. Identifiable information is held by QAIHC only if permission has been received from the ATSICCHS and its use by QAIHC has been consented to by the individual. Personal information held at QAIHC is collected for the purposes of health research only, consistent with its APP obligations. QAIHC data contains both longitudinal and cross-sectional data on episodes of care, client contacts, health risk factors, maternal and child health, MBS data, chronic disease, management of medications and workforce. For detailed information relating to datasets available to QAIHC refer to table 1 or contact QAIHC HIT for further information.

Data is extracted from the health service Electronic Medical Record (EMR) through a Clinical Audit Tool (CAT4) and then sent to the Practice Aggregation Tool (PATCAT) hosted on the QAIHC server. Data available from PATCAT can then be stored in the form of Microsoft Excel file format, Comma Separated Values, PDF and PNG image files. Other data sets accessed by QAIHC are in the form of XML, CSV files, MS Forms, MS Lists and Power BI files. Data is both qualitative and quantitative. Member services that supply information to QAIHC retain ownership of that information. Each service

has responsibility for ensuring the accuracy, timeliness and integrity of their data as outlined in the QAIHC Data Deeds. However, QAIHC provides support to ATSICCHS through quality improvement activities (section 7), Data Systems and Reports Workshops, webinars, teleconferences and reports (outlined in section 5).

Table 1. Data sets held at QAIHC

HIT data sets:

Data	Unit Level	Data Format	Data Custodian	Frequency	Years of Data Available
PAT Database • PAT BI Delta • GIS tagged	Aggregated, deidentified row Level	SQL Management Studio, URL	QAIHC	Monthly	2014 – present
Other ATSICCHO Data	Aggregated and deidentified service level data	Excel or CSV	QAIHC	Annual/As requested	2023 -onwards

Projects and Research:

Data	Unit Level	Data Format	Data Custodian	Frequency	Years of Data Available
Immunisation pilot project	Aggregated, Service Level	Quantitative, XLS	QAIHC	Monthly	2014
STI pilot project	Aggregated, Service Level	Quantitative, XLS	QAIHC	As requested	2017
Smoking data	Aggregated	Quantitative, PDF	Queensland Health	Monthly	2012 – present
HHS data – perinatal and separations	Aggregated, HHS Level	Quantitative, XLS	Queensland Health	As requested	2012-2022
Census, ATSIHS, ATSISS	Aggregated	Quantitative, XLS, PPT	Australian Bureau of Statistics	As requested	2006, 2011, 2016, 2021
Population Estimates by Indigenous Status	Aggregated	Quantitative, XLS	Government Statistician (QLD)	Annual	2012-2015
Medicare data	Aggregated, Medicare Local Level	Quantitative, XLS	Department of Human Services	Quarterly	2012 - present
Burden of Disease and Causes of Death	Aggregated QLD data by Indigenous status	Quantitative, XLS	AIHW	As requested	2019 - present

QAIHC Data Process Flow & Life Cycle

1. Creation and Collection of Data

The history of the development of the QAIHC indicators and data products are summarised in Box2. In 2009 Member services were involved in the development of the QAIHC indicators and endorsed the agreed definitions and standards as specified. These standards and definitions are reviewed by the QAIHC Clinical Leaders Forum and RAICCHO's. There are a number of data collection standards QAIHC adheres to throughout the data creation and collection phase. Since 2009 HIT have purchased Pen CS

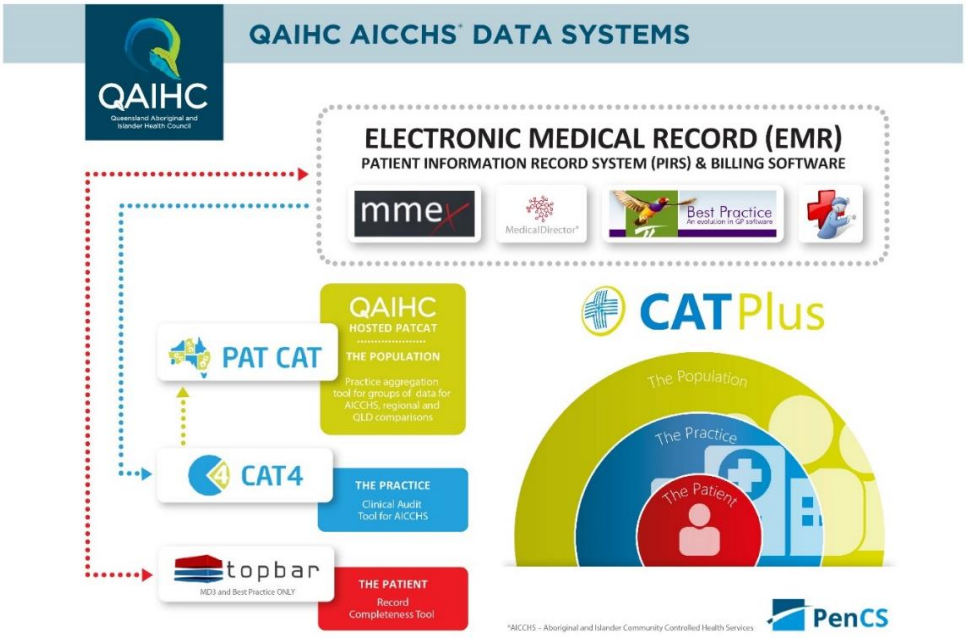
CAT licenses for Member Services to utilize within their practice for analysing and reporting on their own data. In 2015 QAIHC purchased PATCAT, which allows Member services to upload their CAT data set on a monthly basis to QAIHC.

Data extraction is automated through a PenCS scheduler (where services choose to do so), and sourced from service EMRs including Communicare, Best Practice and Medical Director. MMEx was made compatible with PenCS tools as of June 2015. Aggregated EMR information is collected monthly through the Member services CAT4. A copy of the data extract is stored locally in the allocated file directory of the member service. The CAT4 extract is de-identified and sent to the QAIHC PATCAT to access for further analysis (see Figure 2). The PATCAT tool is a reliable and secure information management platform that facilitates the use of data, while protecting the confidentiality and minimising the risk of inappropriate use of the data. All ATSICCHS data is saved and stored in a secure environment.

Box 2. History and development of the QAIHC Indicators and HIT work activities

2007-2008:	QAIHC Clinical Centre for Research Excellence (CCRE) was funded by the Office of Aboriginal and Torres Strait Islander Health (OATSIH) to undertake the Health Information Project (HIP). The HIP project developed a minimum health information data set to monitor and report health outcomes and support clinical quality improvement: measuring performance on a number of key risk factors, clinical care activities and chronic diseases.
2009:	QAIHC Core Indicators set coded as a report in PEN Clinical Auditing Tool (CAT)^{TM} system which is web-based and integrates with the ATSICCHS clinical Electronic Medical Record systems (EMRs) – Operational October 2009. Service Level Agreements were developed and signed by all involved. October 2009, 6 services submit data to QAIHC. EMR systems integrated with PEN CAT – Medical Director, Best Practice.
2010:	Close the Gap (CtG) Collaborative Continuous Quality Improvement (CQI) program commences July 2010 in 22 services. Data submission process fully automated for 13 services. QAIHC pages built into Australian Primary Care Collaborative (APCC) portal for service feedback.
2011:	EMR systems integrated with PEN CAT – Communicare, Medical Director, and Best Practice. Data submission to QAIHC and for CtG Collaborative automated for all services. 18 ATSICCHS submitting data.
2012:	Benchmarking Report 3 distributed to ATSICCHS. Created QAIHC Data Governance Protocols. Five Regional Profile Reports were created. External Report 1 developed and distributed to external stakeholders.
2013:	Benchmarking Report 4 distributed to ATSICCHS. New data agreements with members. 15 Practice Health Atlas and 17 executive summaries completed. 5 Regional Profile Reports created. Development and automation of individual ATSICCHS Push Reports. CtG Collaborative name changed to Aboriginal and Islander Community Controlled Health Services Clinical Excellence (ACE) Program. QAIHC nKPI report developed and distributed.
2014:	Consolidation of the health information system with the development of new indicators for maternal health, sexually transmitted infections and immunisation. Push reports created for 11 services, 15 PHAs and 17 executive summaries. 5 Regional Profile Reports completed. Benchmarking Report 5 released. Organisational restructure of QAIHC's Data Management Unit became the Health Information Unit.
2015:	EMR systems integrated with CAT4 – MMEx. Transitioned 24 member's data from Improvement Foundation QI Connect web portal to QAIHC Practice Aggregation Tool (PATCAT). PATCAT is used to securely collect, store and interpret De-identified aggregated data, including QAIHC Indicators. Benchmarking Report 6 released. PATCAT made available a suite of data that was previously not available to report on.
2016:	New data agreements with members. Purchase and implementation of Topbar, site visit support and training members on use of Topbar to improve data quality. Uptake of Topbar by members using MD and Best Practice. PHAs completed for 15 members.
2017:	Development of Data Request Form. Continued training on use of PATCAT and Topbar. Focus on improving data quality within PATCAT. Monthly reports created for 2 member services. Organisational Health Check Reports completed for 6 members. Organisational restructure of QAIHC's Health Information Unit became the Health Information Team.
2018:	Release of QAIHC HIT Work Plan for 2018/2019. Investment into data visualisation tool Tableau for report automation. Facilitation of quarterly Data Systems and Reports Workshops and bi-monthly webinars for members. Access to National Key Performance (nKPI) and Online Services Reporting (OSR) in negotiation. New Health Information Data Services Deeds to replace existing data agreements.
2019:	Release of Service profile reports and draft QLD of QLD Snapshot Report. Continuation of QTRly MBS reports. DATA Deeds and Governance Protocols released and executed for majority of services
2020 - 2021:	Report redesign working group created, developed action plan and recommended changes in reports based on members' feedback.

Figure 2. EMR/PIRS, Topbar, CAT4 and PATCAT/QAIHC Data Flow



2. Data Storage and Access

Data storage and access responsibilities lie with each ATSICCHS. Data accessed and stored by QAIHC is saved electronically, held at the QAIHC Main Network Server. Access to the data is restricted to the QAIHC CEO, ICT and the HIT. Data may be accessed as per approval granted on Data Consent Form when required by other QAIHC staff. Data that is housed in the QAIHC Brisbane Office Main Server contains de-identified, aggregated records submitted by member services as well as personal information collated for health research (Table 1). The purpose of storing data from participating member services is to enable timely feedback and analysis of the data at service, state and regional levels. The secretariat function of the management of ATSICCHS data is the responsibility of the HIT. Data may be accessed for reasons including but not limited to technical support, data manipulation and analysis and reporting to support quality improvement.

3. Data Quality and Analysis

Analysis of data by QAIHC will be undertaken to inform policy development, clinical strategic planning and support ATSICCHS performance monitoring. Furthermore, data may be used for funding applications, sector advocacy, regional and health service planning and profiling and quality improvement. All services submitting data receive copies of the reports generated by QAIHC HIT. Some reports are also generated for dissemination to stakeholders outside of QAIHC and its members. In this instance, only state-wide or regional data will be presented, and services will not be identified. Analysis may include statistical and time trend analysis, geospatial mapping and prediction or modelling of trends and monitoring of data quality. All analysis conducted is the responsibility of the HIT and will adhere to data release processes including the aggregation of data where appropriate, de-identification of patients and services, suppression of small cell counts (i.e. under 5) and an assessment of risks and confidentiality with respect to both the numerator and denominator.

Data analysis can be conducted by ATSICCHS using their EMRs, billing systems, internal databases and dashboards, the Clinical Audit Tool(CAT), Practice Aggregation Tool CAT, OCHREStreams and the Health Data Portal. At QAIHC, further analysis is conducted primarily in Power BI but also using

software such as SPSS, Microsoft Excel and other software as necessary. Regular data testing and quality assurance is undertaken to ensure accurate and appropriate information is being represented for data analysis and reporting.

QAIHC members may be engaged by third parties (including research bodies) to be involved in research and research related projects. QAIHC can provide advice and support prior to the commencement of any research or project with our member services around engagement with ATSICCHS. Any research undertaken must follow ethical guidelines and standards and undergo ethical approval by the research organisation concerned. QAIHC strongly recommends services ensure they understand the processes, aims and outcomes of the research as well as assessing what benefit it will have to the community involved. The member service should also check that the research is consistent with the consent of individuals regarding use of their personal information and that the research organization has appropriate confidentiality and privacy policies in place and a data breach response plan that are consistent with the member services obligations.

4. Publication and Release of Data

Reports and data are often requested from the HIT. These requests should be completed using the HIT Data Request Form and will then be recorded in a request database. The request database contains information including the staff member the request was actioned by; the name of the person requesting the data and the organisation they work for; details of what data, map or graph the request is about; the intended use of the data; what QAIHC region the request relates to if applicable; whether the use of the data consistent with the consent of individuals regarding use of their personal information (if relevant); whether the organization has appropriate confidentiality and privacy policies in place and a data breach response plan that are consistent with the member services obligations; the date the Data Release and Use Deed was signed by the organization; the date the data request was completed; whether or not the data was released; time taken to respond and complete the request; whether member service CEO approval was required; and any further comments about the data.

Data requests should be submitted to QAIHC in written form using the HIT Data Request Form. Requests should follow the QAIHC Release of Data Process (see Figure 3). Generally requests come from QAIHC staff including the QAIHC CEO, Managers, Regional Coordinators, Regional RAICCHO staff, the National Aboriginal Community Controlled Health Organisation (NACCHO) and other affiliates. There are no fees for data requests provided by HIT.

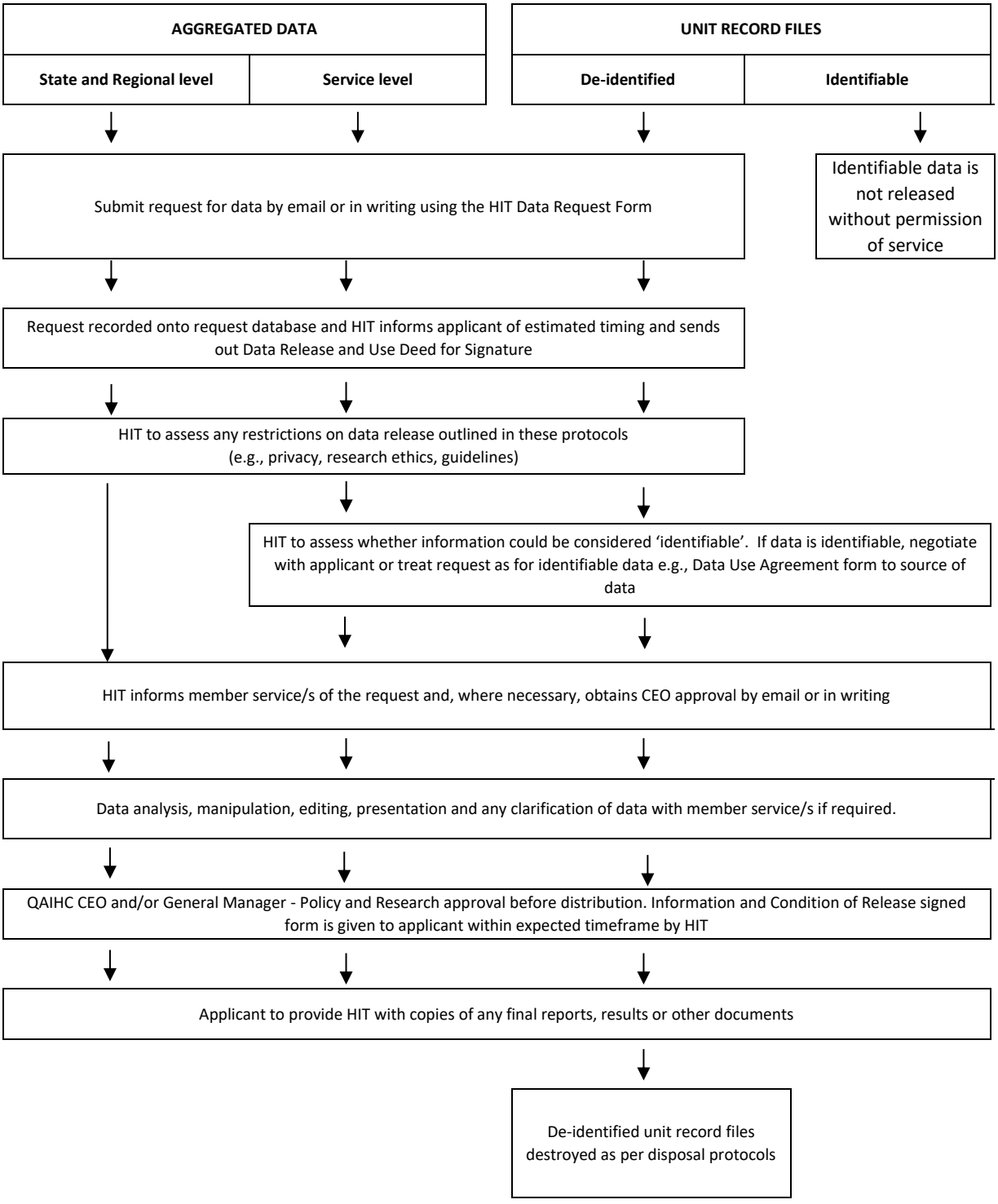
The requestee will receive a Condition of Release disclaimer, outlining the terms of the use of data provided. This form will require to be signed and completed before release of data. An example of a condition of release is the data must include QAIHC as the source of information. E.g., tables and text of final reports and formal correspondence authors should first cite the HIT, followed by the year/s of data and the date the data was released. For example: *Health Information Team, 2010-2011, unpublished (released on 12/10/2012).* Publication and release of data should always acknowledge and thank relevant member services for providing their data.

Publication and release of data requires approval of the QAIHC CEO and/or General Manager - Policy and Research and service CEO if required and must be accompanied by a signed Conditions for Release. Upon assessment of the data request, the Member Service involved will be contacted via a Data Use Agreement form for permission to release data. Depending on the data request, dissemination of the data may be at a service level, regional and/or state level.

Personal information (such as names, addresses, phone numbers and date of birth) will never be released in publications or reports or to any third parties. Personal information is only collected for the purposes of health service planning.

Where a patient has requested their data not be used for research purposes, including de-identified data, it is possible to remove the patient data from the CAT4 (and therefore QAIHC PATCAT) database. Members can access the CAT Patient Consent Withdrawn Quick Reference Guide to follow the correct process.

Figure 3: QAIHC Release of Data Process



5. HIT Data Products and Output

In consultation with member services, QAIHC publishes several reports which include:

- MBS dashboard
- Service level QAIHC Indicator dashboard and report
- Service Profile dashboard and report
- Community Profile dashboard
- QAIHC State-wide and Regional Snapshot Reports
- Customized Reports (for e.g. Organisational health check report card or GIS mapping)

These reports/dashboards are generated monthly, quarterly, annually or biannually as appropriate. Please see 2023 Health Information Team Plan for further information. Other reports may be collated as requested.

6. Data Retention and Disposal

Custodians of information must also consider the appropriate destruction of information. Where legal requirements exist, they must be complied with. Otherwise, consent agreements should exist which include details regarding data destruction. Alternatively, identifying or potentially identifying information about individual or discrete communities of Aboriginal and/or Torres Strait Islander peoples should be destroyed as soon as there is no longer a research or operational requirement for such details or an ethical or regulatory obligation to store the data.

QAIHC's ICT server array is stored in a secured dedicated server room with controlled access and dedicated environmental controls. The system is fully redundant at all levels. Servers, power circuits, and Uninterrupted Power Supply (UPS) systems.

QAIHC ICT Policies require strict adherence to data management and access, data is never disposed of, and all files are backed up on two different systems. Original to Network-attached Storage (NAS) being the first stage then, the NAS Backups are replicated to a cloud backup system with full virtualisation capacity.

Communication and Collaboration for Continuous Quality Improvement (CQI) and Data Support

QAIHC aspires to empower sustainable an Aboriginal and Torres Strait Islander Community Controlled Health Sector, underpinned by cultural safety, strong leadership, governed by principles of self-determination (QAIHC Strategic Plan 2021 – 2024). CQI in ATSICCHS is the ongoing forward focused process of continued learning and sharing. A CQI environment is explained as one where data is systematically collected and used to maintain high quality or make improvements where required.

As a state peak body, the focus of CQI is on providing support for Member services, including through training and mentoring and facilitating access to tools and resources, managing CQI networks, structured data sharing, sense-making and reporting back to services, addressing data infrastructure functionality, facilitating CQI data sharing and sense-making and supporting Members needs as appropriate across the network. This work is supported through CQI coordination roles.

Core Components of the National CQI Framework for Aboriginal and Torres Strait Islander Primary Health Care 2015-25 outline the importance of:

Clinical data infrastructure and functionality for CQI	All primary health care providers have access to flexible, user-friendly, clinical data infrastructure and functionality that supports PDSA and other CQI activities. Primary health care provider teams need access to clinical data infrastructure and functionality that allow them to extract and use data in real time for PDSA cycles and other CQI activities.
CQI Data sharing and sense-making	CQI data sharing and sense-making within and between sectors by primary health care providers' regional, state/territory and national representative organisations results in widespread shared learning and underpins policy and investment and strategies for improvement at all levels. Sharing of primary health care providers' de-identified data at different levels within and between sectors allows their representative organisations to make contextualised comparisons, tailor support, demonstrate achievements, and highlight areas for improvement (sense-making). Quality indicators are necessary for data sharing and sense-making. Quality indicators are necessary for CQI data sharing and sense-making.
PDSA cycles	PDSA cycles as a team function and incorporating all steps including service redesign, are embedded in the everyday practice of services/ practices/centres. Plan–Do–Study–Act (PDSA) is an internationally recognised method for primary health care providers to systematically review their performance in meeting client needs, providing high quality care and improving client outcomes. It is a series of steps undertaken cyclically, that guides teams in the routine use of data as a basis for dialogue to identify priorities for action, develop and test strategies for improvement, and implement service redesign. Quality indicators are necessary for PDSA cycles. Quality indicators are necessary for PDSA cycles.

The QAIHC HIT provides CQI and data support to member services through the following activities:

- QAIHC Website resources
- QAIHC Sector Leader Magazine
- Monthly Data Network online meetings
- HIT Helpdesk Support
- Bi-annual Data Systems and Reports Workshops
- User Guides and Manuals
- Reports and dashboards listed in Section 5
- Timely and accurate responses to data requests
- Presentations at relevant regional and state meetings
- Clinical Software, Clinical Audit Tool (CAT4), Practice Aggregation Tool (PATCAT) and Topbar training
- Clinical Leaders Forum participation and presentations as required

The QAIHC State-wide Clinical Leaders Forum (formerly Lead Clinicians Group) was established by QAIHC in 2011, acting as an advisory body for data governance among other purposes. The Clinical Leaders Forum (CLF) advises on the collection and use of data, via an email network and biannual meetings. The focus of this group in relation to data includes:

- Sharing successful continuous quality improvement strategies across ATSICCHS
- Using data to improve health outcomes in communities
- Using audit, evaluation and performance management to ensure high quality care
- Sharing clinical protocols and best practice evidence relevant to members.

Future Directions and Management of Data

The QAIHC Indicators may be expanded or modified to meet emerging information needs, and/or to minimise reporting requirements arising. As new indicators and data sets are developed, they will be included in this document.

QAIHC is responsible for overseeing the implementation, monitoring and revision of these Protocols and any related Subsidiary Agreements. It is anticipated that QAIHC Data Governance Protocols will be reviewed annually. Incorporation of feedback from stakeholders will be considered and included in the document where necessary.

As Regional Aboriginal and Islander Community Controlled Health Organisations (RAICCHOs) are established, each RAICCHO may have their own processes and protocols around data sharing and the release of health information.

Definitions

***Aggregated Data**:*

Aggregated data describes data combined from several measurements. When you aggregate data, you replace groups of observations with summary statistics based on those observations. For example, service level data may be combined to create region level data.

Confidentiality:

The restricted disclosure of personal information to authorised persons, entities and processes at authorised times and in an authorised manner.

Clinical Audit Tool (CAT4):

CAT4 (Clinical Audit Tool4) provides essential patient health graphs, charts and reports to best assist practice staff to implement and drive process change ultimately improving patient health outcomes.

Data Custodian:

Data Custodians are responsible for the safe custody, transport, storage of the data and implementation of business rules. Data Custodians are responsible for the technical environment and database structure.

Data Governance:

The discipline embodies a convergence of data quality, data management, data policies, business process management, and risk management surrounding the handling of data in an organisation.

De-identified data:

Identifiers have been removed and replaced by a code, but it remains possible to re-identify a specific individual by, for example, using the code or linking different data sets. Information which has been stripped of details such as individual names, addresses, dates of birth, death or other events, or in certain circumstances Aboriginal community identifiers; or where such details have been sufficiently altered to render the identification of individuals or communities unlikely. There are cases where aggregated data, apparently stripped of identifiers, may permit individuals or communities to be identified (e.g. an uncommon medical condition). Special consideration should be given to ensuring the privacy of individuals and communities in such circumstances.

Health Data Portal: The Health Data Portal is a web-based tool that is used by Aboriginal and Torres Strait Islander Health Services to submit nKPIs, OSR and HCP reporting data by direct upload from their Electronic Medical Record.

Identifiable data:

Any data that could, either on its own or by matching with other data sets, allow the identification of an individual, including a body or association of persons. Examples of identifiers include an individual's name, image, date of birth, date of death, or address.

Management (of information):

Includes issues such as collection, ownership, storage, security, access, release, usage, reporting and interpretation of information.

Ownership (of information):

The right to control the dissemination and use of personal information. Ownership of Aboriginal and Torres Strait Islander health and health-related information may be on an individual or collective

community basis. (These special ownership rights are recognised for the purpose of these Protocols, but it is noted that current legislation does not recognise this type of ownership).

***OCHREStreams**:*

A web-based reporting tool made redundant in 2018.

Practice Aggregation Tool (PATCAT):

PATCAT is a web-based solution that does not require installation. Aggregates de-identified health service data and displays the information through a collection of graphs, charts and report useful for time series analysis.

Privacy (of Aboriginal and Torres Strait Islander community information):

The right of an Aboriginal and Torres Strait Islander community to exercise appropriate control over the availability and dissemination of Aboriginal and Torres Strait Islander community information to others.

Privacy (of individual information):

The right of an individual to exercise appropriate control over the availability and dissemination of personal information about themselves to others.

Potentially identifiable information:

Information from which names, addresses and precise dates have been removed, but from which it might still be possible to identify an individual.

Reciprocity:

A mutual obligation exists among members of Aboriginal and Torres Strait Islander families and communities to achieve an equitable distribution of resources, responsibility and capacity and to achieve cohesion and survival of the social order. This mutual obligation extends to the land, animals and other natural elements and features. In contemporary settings the value of reciprocity continues in various forms and may vary between locations. Examples include the redistribution of income, benefits from the air, land and sea, and the sharing of other resources such as housing.

Topbar:

Topbar is an interactive data quality tool for all staff to be used with MD3 and Best Practice. It needs to be installed on the server and for each user profile

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Appendix 1. Map of QAIHC ATSICCHS Members, 2022

Appendix 2. Supporting Documentation

- QAIHC Strategic Plan 2021 - 2024
- QAIHC Core Indicators
- QAIHC Health Information Data Services Deed
- QAIHC ICT Policy
- QAIHC Data Breach Response Plan
- QAIHC Workplace Confidentiality Agreement
- QAIHC HIT Data Use Agreement
- QAIHC HIT Conditions of Release

QAIHC Partner Agreements and Privacy Policies

- NACCHO Data Governance Protocols
- PCS Clinical Audit Data and Aggregation of Practice Data Policy Statement – PEN computer systems Pty Ltd http://www.clinicalaudit.com.au/downloads/PCS_Data_Agg_Policy_statement.pdf
- PEN Computer Systems http://pencs.com.au/privacy-policy.html

Appendix 3. National Aboriginal and Torres Strait Islander Health Data Principles

All organisations with significant responsibilities in Aboriginal and Torres Strait Islander health data should encourage the application of these principles and establish meaningful partnerships with Aboriginal and Torres Strait Islander Australians.

Mindful of Aboriginal and Torres Strait Islander peoples' understanding of ownership, including ownership of personal and community information, and any relevant agreements with various parties, including governments, these principles set out a culturally respectful foundation for the collection, storage and use of their health and health-related information.

Principle 1

The management of health-related information about Aboriginal and Torres Strait Islander persons must be ethical, meaningful, and support improved health and better planning and delivery of services.

Principle 2

The analysis, interpretation and reporting of Aboriginal and Torres Strait Islander health and health-related information should, where feasible, occur collaboratively with Aboriginal and Torres Strait Islander peoples.

Principle 3

The privacy and confidentiality of Aboriginal and Torres Strait Islander people will be protected in accordance with any relevant legislation and privacy codes.

Principle 4

Aboriginal and Torres Strait Islander peoples should be informed at the point of service that attendance/participation may contribute to administrative or mandatory data collections and that such data will be used to improve the quality, coverage and scope of health services and protect the public health. Data collection agencies and data custodians should have a policy that provides this information to people at the point of data collection and appropriate governance arrangements to review its implementation.

Principle 5

In general, free and informed consent should be obtained from Aboriginal and Torres Strait Islander peoples prior to any information management activities, except where mandatory reporting or legislative provisions apply. Otherwise, where there is a proposal to initiate an information management activity without the consent of Aboriginal and Torres Strait Islander peoples, it must be clearly demonstrated both that the activity will advance the interests of Aboriginal and Torres Strait Islander peoples and that it is impractical and infeasible to obtain further specific consent.

The value of the resources required to collect and use information should be assessed in the light of the potential benefit to Aboriginal and Torres Strait Islander peoples' health.

Principle 7

The collection, collation and utilisation of information should be conducted in the most efficient and effective manner possible and minimise the burden on Aboriginal and Torres Strait Islander people.

Principle 8

Systematic and ethical processes for sharing information should be encouraged to assist in policy, planning, management and delivery of health services to Aboriginal and Torres Strait Islander people.

Principle 9

Aboriginal and Torres Strait Islander communities should be provided with feedback about the results and possible implications arising from data analysis.

Principle 10

Information collections require regular review and refinement in order to ensure ongoing relevance to service delivery and the potential for improved health outcomes.

Principle 11

Cultural respect and security of data practices must be promoted across all collections. Aboriginal and Torres Strait Islander individuals and communities should be afforded the same ethical and legal standards of protection as are enjoyed by other Australians. This may require the development and application of methods that are different to or in addition to those in mainstream data collections.

Endorsed by AHMAC October 2006