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Acronyms

ACE – AICCHS Clinical Excellent Program

AHMAC - Australian Health Ministers Advisory Council

AICCHS – Aboriginal and Islander Community Controlled Health Service

APCC – Australian Primary Care Collaborative

APP – Australian Privacy Principles

CQI – Continuous Quality Improvement

CtG Collaborative – Close the Gap Collaborative

DMU – Data Management Unit, QAIHC

EDocx – Electronic Data Exchange

EMR – Electronic Medical Record

GRAHNITE - GeneRic HeAlth Network Information Technology for the Enterprise

HREOC - Human Rights and Equal Opportunity Commission

ICT – Information, Communication and Technology

IF – Improvement Foundation

IPPs – Information Privacy Principles

LCG – Lead Clinician Group

NHMRC – National Health and Medical Research Council

nKPIs – National Key Performance Indicators

OSR – Online Services Reporting (previously OATSIH Services Reporting)

PDSA Cycles – Plan, Do, Study, Act Cycles

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 QAIHC on behalf of its member services (see Appendix 2 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. 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 Analysis
4. Publication and Release of Data
5. Preservation and Deposit Data
6. Communication and Collaboration for Continuous Quality Improvement (CQI) Support
7. Future Directions and Management of Data

Background

The Queensland AICCHS and QAIHC have recognised the need to build the evidence base to support increased and continued investment within the Aboriginal and Torres Strait Islander health services sector in Queensland. The functions of the Data Management Unit (DMU) are to:

1. Improve the quality, utility and value of clinical information and information systems
2. Build capacity within the Sector for the ongoing analysis, monitoring and reporting of health data
3. Provide reports and analyses in support of the QAIHC strategic goals and to support quality improvement within individual services.

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 the Queensland Aboriginal and Islander Health Council (see Appendix 2) participating in QAIHC’s AICCHS Clinical Excellence (ACE) Program (formerly Close the Gap collaborative) and, when necessary, Regional Aboriginal and Islander Community Controlled Health Organisations (RAICCHOs). These protocols form the basis of local partnership data agreements between the Aboriginal and Islander Community Controlled Health Services 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

The data collected, housed and used by QAIHC must comply with the Commonwealth Privacy Act, 1988 and the Australian Privacy Principles (APPs) contained in schedule 1 of the Privacy Act, effective as of 12 March 2014. QAIHC recognises the principles outlined by the RACGP, NHMRC, NACCHO, HREOC and AHMAC. Supporting documentation for these protocols written by QAIHC, QAIHC partners and external bodies are listed as in Appendix 1. The guiding principles of the QAIHC Data Governance Protocols (Box 1) are adopted from the guiding principles identified in the NSW Aboriginal Health Information Guidelines (1998) and the AIHW, for the Australian Health Ministers Advisory Council: National Aboriginal and Torres Strait Islander Health Data Principles (Appendix 3).

Box 1. Guiding Principles of QAIHC Data Governance Protocols

<table>
<thead>
<tr>
<th>Principle</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Principle 1</td>
<td>The management of health and health-related information about Aboriginal peoples must be ethical, transparent, meaningful and useful to Aboriginal and Torres Strait Islander peoples, based on consistency with the guidelines in the National Aboriginal and Torres Strait Islander Health Strategy (1989), and the NAiHO Report on Aboriginal and Torres Strait Islander Research Ethics (1987). Such determinations may be made at State or local level, as appropriate.</td>
</tr>
<tr>
<td>Principle 2</td>
<td>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.</td>
</tr>
<tr>
<td>Principle 3</td>
<td>The analysis, interpretation and reporting of Aboriginal and Torres Strait Islander health and health-related information should occur collaboratively between the parties to the QAIHC Data Governance Protocols.</td>
</tr>
<tr>
<td>Principle 4</td>
<td>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.</td>
</tr>
<tr>
<td>Principle 5</td>
<td>Health service providers should inform Aboriginal and Torres Strait Islander peoples about how and why their health information is collected and used.</td>
</tr>
<tr>
<td>Principle 6</td>
<td>While health service providers have common information needs, there is also diversity among them which generates unique information requirements.</td>
</tr>
<tr>
<td>Principle 7</td>
<td>The parties should be encouraged to share information that may assist in planning, management and delivery of health services for Aboriginal and Torres Strait Islander peoples.</td>
</tr>
<tr>
<td>Principle 8</td>
<td>Information collections require regular review and refinement by the parties to ensure relevance to service delivery and compliance with agreed information needs.</td>
</tr>
</tbody>
</table>
Ownership and Custodianship of Information

Aboriginal and Islander Community Controlled Health Services (AICCHS) are recognised as the owners of any data submitted to the QAIHC data management unit. QAIHC is data custodian for a number of data sets. Custodianship of information about Aboriginal and Torres Strait Islander peoples confers a number of responsibilities including:

- ensuring the information record is 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.

AICCHS 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.

As data custodian, QAIHC acknowledges the need to adhere to strict privacy and confidentiality issues, to maintain integrity and respect to the data and to the members we represent. QAIHC has a responsibility to its member services and regional entities to protect and manage data according to best practice. This includes ensuring that:

- identifiable information is not released publicly
- identifiable information cannot be derived from disseminated data
- data is maintained and accessed securely

Data Sets at QAIHC

These data sets contain aggregated and de-identified information of patients whom have attended an AICCHS, as well as subsets of information on survey populations. Personal information is also held at QAIHC, collected for the purposes of health research (Section 16B) and therefore is not a breach of APP obligations. QAIHC data contains both longitudinal and cross sectional data on health risk factors, maternal and child health, chronic disease and management of medications and workload. Data is available in the form of Microsoft Excel files and Access files, XML files, MapInfo Tables and SAS Tables. 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. However, QAIHC provides support to AICCHS through quality improvement activities outlined in detail in section 6. For further information relating to specific data sets please contact QAIHC DMU.
Table 1. QAIHC Current and Future Data

<table>
<thead>
<tr>
<th>QAIHC Current Data</th>
<th>Unit Level</th>
<th>Data Custodian</th>
<th>Frequency</th>
<th>Years of Data Available</th>
</tr>
</thead>
<tbody>
<tr>
<td>QAIHC Core Indicators</td>
<td>Aggregated, Service Level</td>
<td>QAIHC</td>
<td>Monthly</td>
<td>2009 – present</td>
</tr>
<tr>
<td>Practice Health Atlas data</td>
<td>Unit Record File, De-identified (Postcode level)</td>
<td>QAIHC</td>
<td>Annually/As requested</td>
<td>2010 – present</td>
</tr>
<tr>
<td>APCC Indicators</td>
<td>Aggregated, Service Level</td>
<td>Improvement Foundation</td>
<td>Monthly</td>
<td>2009 – present</td>
</tr>
<tr>
<td>nKPIs</td>
<td>Aggregated, Service Level</td>
<td>AIHW</td>
<td>Biannually</td>
<td>2014</td>
</tr>
<tr>
<td>OSR</td>
<td>Aggregated, Service Level</td>
<td>AICCHS</td>
<td>Annually</td>
<td>Not available at time of publication</td>
</tr>
<tr>
<td>GIS Extract</td>
<td>Personal Information - Unit Record File, Identifiable (Address level)</td>
<td>Under Ethics Review</td>
<td>As requested</td>
<td>Not available at time of publication</td>
</tr>
</tbody>
</table>

Future Data

| QAIHC Indicators Maternal & Child Health | Aggregated, Service Level | QAIHC | Monthly | In development - |
| QAIHC /NACCHO Indicators Sexually transmitted infections | Aggregated, Service Level | QAIHC | Monthly | In development |
| QAIHC Indicators Immunisation           | Aggregated, Service Level    | QAIHC | Project based | In development - Not available at time of publication |

QAIHC Data Process Flow & Life Cycle

1. Creation and Collection of Data

The history of the development of the QAIHC indicators and data repository are summarised in Box2. Data extraction is automated, and sourced from service Electronic Medical Records (EMRs) including Communicare, Best Practice and Medical Director (MD). Some services also use MMEx, however at this stage data extraction is not automated. AICCHS have Data Custodianship Agreements with QAIHC and with the Improvement Foundation (IF) and QAIHC has an agreement with IF (see Appendix 3 and 4).
Box 2. History of the development of QAIHC indicators and data repository

<table>
<thead>
<tr>
<th>Year</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>2007-2008:</td>
<td>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.</td>
</tr>
<tr>
<td>2009:</td>
<td>QAIHC Core Indicators set coded as a report in PEN Clinical Auditing Tool (CAT)™ system which is web-based and integrates with the AICCHS 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.</td>
</tr>
<tr>
<td>2010:</td>
<td>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.</td>
</tr>
<tr>
<td>2011:</td>
<td>EMR systems integrated with PEN CAT – Communicare, Medical Director, and Best Practice. Data submission to QAIHC and for CtG Collaborative automated for all services.</td>
</tr>
<tr>
<td>2012:</td>
<td>Consolidation of the health information system with the possible addition of some indicators for mental health, dental health, maternal health, sexually transmitted infections and blood borne viruses. Benchmarking Report distributed to AICCHS and feedback received. 5 Regional Profile Reports were created.</td>
</tr>
<tr>
<td>2013:</td>
<td>Benchmarking Report distributed to AICCHS in May and feedback received. Push reports were developed and automated for each of the AICCHs. 15 Practice Health Atlas and 17 executive summaries completed. 5 Regional Profile Reports created.</td>
</tr>
<tr>
<td>2014</td>
<td>Consolidation of the health information system with the possible addition of some indicators for, maternal health, sexually transmitted infections and immunisation. Access to National Key Performance (nKPI) and Online Services Reporting (OSR) is currently being negotiated.</td>
</tr>
</tbody>
</table>

There are a number of data collection standards QAIHC adheres to throughout the data creation and collection phase. The repository is supported by a data dictionary, which sets out agreed data definitions, classifications and standards for data being collected. Member services were involved in the development of these indicators and have agreed to comply with the agreed definitions and standards as specified. These standards and definitions are currently under review by the Lead Clinician Group (LCG).

Aggregated EMR information (APCC data and the QAIHC Indicators) are submitted monthly either directly or through a Token or certificate of authentication in the Clinical Audit Tool to the Improvement Foundation (IF) QIConnect Portal. A copy of this data is stored locally in the allocated file directory of the member service. An excel file (a copy) of the service data is downloaded by QAIHC from the QIConnect Portal and then saved and stored in secured environment in the QAIHC data repository and later accessed by the Data Management Unit for further analysis (see Figure 2). Services are able to see their data uploaded onto the QIConnect portal approximately 24 hours after data submission.
The QAIHC data repository is a reliable and secure information management system which facilitates the use of data, while protecting the confidentiality of the data and minimising the risk of its inappropriate use. To ensure this environment, QAIHC must comply with the following:

- the Australian Institute of Health and Welfare Act 1987, section 29 and the Institute’s Information Privacy Principles;
- QAIHC staff who, in the course of performing their duties may be required to handle confidential and / or sensitive material and are required to sign a Workplace Confidentiality Agreement and comply with the Privacy Amendment (Private Sector) Act 2000 as part of QAIHC’s induction process;
- Staff accessing the Repository must sign an IT Security Clearance form;
- All work performed by consultants, contractors, seconded staff, visiting fellows and students which involves access to information and other identifiable information held in the QAIHC Data Repository, must be authorised by contracts which impose information and privacy security requirements.
- Maintain a secure electronic environment for data storage.

The collection, storage and use of health data in Queensland are governed by The Privacy Act 1988:

- Australian Privacy Principles (APPs) – Replaced the IPPs and 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.
QAIHC works with 3rd parties in the collation and analysis of member service data. These third parties must also comply with the APPs and have their Privacy Policies freely available on their websites. Links to the Improvement Foundation and PEN Computer Systems privacy policies can be found in Appendix 1.

2. Data Storage and Access

Data storage and access responsibilities lie with each AICCHS. All QAIHC data are stored and saved electronically in a central Data Management Unit folder, held at the QAIHC Main Network Server. Access to QAIHC data held in the DMU folder is restricted to the QAIHC CEO and the Data Management Unit Team, consisting of:

- DMU Manager (Public Health Medical Officer)
- Public Health Medical Officer (PHMO) Registrar
- Data Management Officer
- Health Information Project Officer
- Regional Coordinators x 2
- SAS Programmer/Data Analyst

QAIHC data repository is housed in the QAIHC Brisbane Office Main Server, which contains de-identified, aggregated records submitted by member services as well as personal information collated for health research (Table 1). The purpose of the data repository is for storing data from all participating member services of the ACE program to enable further collation and timely feedback analysis of the data at service, state and regional levels. The secretariat function of management of the data repository is the responsibility of the Health Information Project Officer and SAS Programmer/Data Analyst. The data repository and other QAIHC data may be accessed for reasons including but not limited to technical support, data development and analysis and reporting to support quality improvement.

3. Data Analysis

Analysis of service data by QAIHC will be undertaken only to inform policy development, clinical strategic planning and performance monitoring. Furthermore, data may be used for funding applications, sector advocacy, regional and health service planning and profiling and quality improvement. All services contributing data receive copies of the reports generated by QAIHCD Data Management Unit. Some reports are also generated for external use ie for dissemination outside of QAIHC and its members. Analysis may include statistical and time trend analysis, geospatial mapping and prediction or modelling of trends. All analysis conducted is the responsibility of the Data Management Unit and will adhere to data principles including the aggregation of data where appropriate, de-identification of patients and services, suppression of small cell counts (ie. under 5) and an assessment of risks and confidentiality with respect to both the numerator and denominator.

At the health service level, data analysis can be conducted using their EMRs, internal databases, the PEN Clinical Audit Tool and the Improvement Foundation Portal. At QAIHC, further analysis is
conducted using software such as SAS, SPSS, MapInfo, Practice Health Atlas, Microsoft Excel, Microsoft Access and other software as necessary.

Additional research and / or projects are conducted with our member services. These projects must undergo the approval from an ethics committee.

4. Publication and Release of Data
In consultation with member services, QAIHC publishes a number of reports which includes:

- Benchmarking Report
- Service Report Cards
- Regional Profiles
- Practice Health Atlases and executive summaries
- Geospatial/demographic reports
- External reports aggregated to state level for public dissemination
- nKPI Report aggregated to state level for public dissemination

These reports are generated annually or biannually as appropriate. Other reports and data may be requested. These requests should have an email trail and will then be recorded in the QAIHC 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 organization they work for; details of what data, map or graph the request is about; what QAIHC region the request relates to if applicable; the date the data request was completed; whether or not the data was released; whether member service CEO approval was required; and any further comments about the data.

Data requests should be submitted to any staff member of QAIHC Data Management Unit in written form (emails are acceptable). Requests should follow the QAIHC Release of Data Process (see Figure 3.). It is envisioned that regular requests will come from QAIHC staff including the Health promotion Manager, health promotion staff, Sector Development Unit Manager, regional coordinators, QAIHC CEO and Regional RACCHO CEOs. Member services are generally exempt from costs for data requests. However, in cases of additional or customised reports, some payment may be requested to cover the additional costs incurred in meeting the software development request(s).

In tables and text of final reports and formal correspondence authors should first cite the Data Management Unit, followed by the year/s of data and the data the data was released. For example: *Data Management Unit, 2010-2011, unpublished (released on 12/10/2012).* Publication and release of QAIHC data must adhere to approval of the DMU manager and service CEO if required. Dissemination of the data maybe required at a service level, regional level and state level but only at the discretion of the DMU.

Personal information (such as names, addresses, phone numbers and date of birth) will never be released in publications or reports or to any 3rd parties. Personal information is only collected for the purposes of health service planning.

Publication and release of data should always acknowledge and thank relevant member services for providing their data.
Figure 3: QAIHC Release of Data Process

AGGREGATED DATA

<table>
<thead>
<tr>
<th>State and Regional level</th>
<th>Service level</th>
</tr>
</thead>
</table>

UNIT RECORD FILES

<table>
<thead>
<tr>
<th>De-identified</th>
<th>Identifiable</th>
</tr>
</thead>
</table>

Submit request for data by email or in writing

Request recorded onto request database and DMU informs applicant of estimated timing

DMU to assess any restrictions on data release outlined in these protocols (eg. privacy, research ethics, guidelines)

DMU to assess whether information could be considered ‘identifiable’. If data is identifiable, negotiate with applicant or treat request as for identifiable data

DMU informs member service/s of the request and, where necessary, obtains CEO approval by email or in writing

Data analysis, manipulation, editing, presentation and any clarification of data with member service/s if required.

Information is given to applicant within expected timeframe by DMU

Applicant to provide DMU with copies of any final reports, results or other documents

Identifiable data will not be available for release at any stage

De-identified unit record files destroyed as per disposal protocols
5. Preservation and Deposit Data

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

With strict adherence to QAIHC ICT Policies, data is never disposed of and all files are backed up using two different systems. File to Disk Cache to Tape being the first one and then File to Disk on a separate system. File restoration is available for any file at any time over the last 3 years with the following caveat less than one week old is current to less than 24 hours, more than one week old current to one week. Prior to 4 years files are available but unreliable. Currently over 1000 backup points are created a week on the Tape Backup system. Media is wiped as required using a DoD wipe and then recycled if possible or destroyed if required.

6. Communication and Collaboration for Continuous Quality Improvement (CQI) Support

Following the end of the APPC Close the Gap Collaborative Wave in June 2011, QAIHC Data Management Unit continues to provide CQI Support to member services through the following activities:

- Advisory Group (Lead Clinician Group)
- QAIHC Website
- Monthly teleconferences
- Collaborative learning workshops twice a year
- Preventative Health Unit Newsletters
- Reports listed in Section 4
- Site Visits
- Presentations at relevant regional and state meetings
- Clinical Software and Clinical Audit Tool Training

The QAIHC Lead Clinicians Group (LCG) was established by QAIHC in 2011. The primary aims:

- To ensure stakeholders work collaboratively to improve the quality and reliability of health and health-related information about Aboriginal and Torres Strait Islander peoples in Queensland;
- To advocate improved access to, and use of, information that can support the planning and delivery of health services; and
- To build confidence in the use of information to improve health by ensuring appropriate consideration is given to cultural and ethical factors associated with the collection, privacy and use of information about Aboriginal and Torres Strait Islander peoples.

The LCG will constitute an advisory body for data governance. The LCG will advise on the collection and use of data, via an email network and biannual meetings.
EDocx, Electronic Data Exchange, is a secure Cloud based tool used to exchange files between the AICCHs and QAIHC Data Management Unit when necessary.

MailChimp, a secure online tool to send marketing campaigns, is utilised to send out de-identified QAIHC DMU reports. A benefit of this tool versus using standard email for distribution is that it collates usage statistics.

7. Future Directions and Management of Data

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 has their own Constitutions containing processes and protocols around data sharing and the release of health information.

It is anticipated that in 2014 work will begin to receive OSR data from OCHRESTreams and billing management data. Plans are currently underway to consolidate all data in one location using SAS. As part of this work, internal quality control reports will be developed to ensure the data received from external bodies is as expected. Further quality assurance processes and standards will also be put into place such as testing to ensure quality of our reporting.

It is envisioned that the peak national body of the Aboriginal Community Controlled Sector (NACCHO) will develop a national data repository of which QAIHC will submit data to.
Definitions

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.

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.

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.

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.

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).

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.

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.

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 (eg. an uncommon medical condition). Special consideration should be given to ensuring the privacy of individuals and communities in such circumstances.

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

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.

**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.
Appendix 1.  Supporting Documentation

QAIHC Documents

- QAIHC Core Indicators
- QAIHC Data Custodianship Agreements
- QAIHC ICT Policy
- Information sheet for staff and patients
- User Documentation QAIHC reporting repository
- QAIHC Data definitions & Codes
- Regional Aboriginal and Islander Community Controlled Health Organisations - Constitutions
- QAIHC Clinical IT Systems & Connectivity in Qld AICCHS
- QAIHC Quality Manual
- QAIHC Workplace Confidentiality Agreement

QAIHC Partner Agreements

- Improvement Foundation DATA Head Agreements a) AICCHs b) QAIHC
- QAIHC / CheckUP MOU
- TORPEDO Services Agreements
- OCHRESTreams participation agreement
- PCS Clinical Audit Data and Aggregation of Practice Data Policy Statement – PEN computer systems Pty Ltd

QAIHC Partner Privacy Policies

- PEN Computer Systems
- Improvement Foundation
- Health First
- The George Institute
  http://www.georgeinstitute.org/privacy-policy

External Documents

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

The Privacy Act 1988, Commonwealth of Australia Canberra


NHMRC (2003) Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research

NHMRC (2006) Keeping Research on Track: A Guide for Aboriginal and Torres Strait Islander peoples about health research ethics

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

National Aboriginal Health Strategy (1989) Department of Aboriginal Affairs, Canberra
Appendix 2. Map of QAIHC AICCHS Members, 2014

QAIHC AICCHS MEMBERS 2014

Scale 1: 13,170,000

06/02/2014
QAIHC Preventative Health Unit, Data Management Unit
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.

Principle 6: 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
Appendix 4. IF Data Agreement 2011

..see attachment
Appendix 5. QAIHC Data Agreement 2013

..see attachment