

## Northern Territory Rheumatic Heart Disease Register

### Data governance framework

Version 1.0 – August 2019

#### Document history

Version	Date	Draft/changes prepared by	Description of changes	Approved by (date)
1.0	12/09/2019	Jessica de Dassel	n/a	K. Hardie (12/09/2019)

#### Introduction

This document describes the data governance framework for the NT RHD Register. It outlines data collection and release processes.

The Northern Territory (NT) Rheumatic Heart Disease Register (hereinafter: “the Register”) is a web-based outward facing database which is used to store patient level data on the diagnosis of acute rheumatic fever (ARF) and rheumatic heart disease (RHD), subsequent care and proposed follow-up provided to people residing in the NT. The Register is maintained by the NT RHD Control Program (hereinafter: “the Control Program”).

#### Purpose of the Register

The primary purpose of the Register is to support the provision and coordination of care for people with a history of ARF and/or RHD.

#### Control Program structures and roles in data governance

**Data steward:** Chief Data Officer, Data Management and System Reporting

**Data custodian:** NT RHD Control Program Data Analyst, in consultation with the Clinical Nurse Manager

**Data owner:** Chief Health Officer

**NT and Central Australian RHD steering committees:** these committees meet on a quarterly basis and review data on diagnoses, delivery of secondary prophylaxis, surgeries and deaths.

**Control Program data meetings:** the NT control program meets monthly to discuss data issues.

## **Data collection and entry**

Data are collected from a variety of data sources including primary health care service databases, specialist letters, echocardiogram reports and hospital discharge summaries. The collection of data is summarised in the *NT RHD Register Data Quality Statement*. Data entry is governed by the *NT RHD Register operational data dictionary*.

## **Data quality**

The Control Program uses several strategies to maintain and enhance data quality. The completeness of diagnoses captured by the Register is cross-checked by reviewing daily reports of people currently admitted to any of the public hospitals in the NT whose hospital records indicate a history of ARF or RHD. In early 2018 data quality assurance was further enhanced by the introduction of surveillance of data from NT Government primary health care services and the public hospital inpatient database. These data review processes are guided by standard operating procedures.

Monthly and biannual standard data quality reviews are conducted to ensure data are as complete and accurate as possible. Ad hoc data audits complement regular scheduled data review processes. Summary information about audits conducted since September 2017 are recorded in a log.

Changes in national and local guidelines, surveillance methods, diagnostic techniques and reporting practices may contribute to differences in case ascertainment over time. Data are subject to change as a result of ongoing data quality and cleaning activities. The *NT RHD Register Data Quality Statement* provides a more detailed description of the key issues relating to the quality of information in the Register.

## **Data storage & backup**

Register data are uploaded from the database into the Department of Health's Data Warehouse (hosted in a secure VLAN environment) on a daily basis. In accordance with the *Records Disposal Schedule - Centre for Disease Control, Department of Health (October 2014)*, data in the Register are retained permanently.

The Register is backed up by Dialog IT and the Department of Health Data Service Centre every night. In addition, Control Program staff backup the Register on a monthly basis. Backup files created by the Control Program are password protected and access is restricted to Control Program staff.

## **Register maintenance and upgrades**

Since 2016 maintenance and upgrades of the Register have been performed by Dialog IT.

## **Access to data from the Register**

In accordance with the *NT Information Act*, use of information from the Register is: "*limited to the primary purpose for collection unless -*

- *it is required or authorised by law;*
- *the person consents;*
- *it is related to the primary purpose (or directly related, for sensitive information) and the person would reasonably expect the use or disclosure;*
- *it is necessary for research or statistical analysis;*
- *it is necessary for some law enforcement purposes, or to protect health and safety.”*

### **Access to data for primary purposes**

Approved users can access the Register directly by logging into the web-based database; administrator and read-only accounts are available. Direct access to the Register is governed by the *NT Rheumatic Heart Disease Register access policy statement*. The application review process and account creation and maintenance are governed by a standard operating procedure.

The login page is an HTTPS webpage and authentication is form-based and encrypted using SSL. Control Program staff are eligible to have administrator or read-only accounts. Health professionals can request a read-only account by completing an application form.

Users with an account must enter their username and password to access the Register. Passwords must meet the password policy's complexity requirements and must be renewed every 30 days by the user. After 60 minutes of idle time, a timeout warning is displayed, if the Register is not used within five minutes of the warning appearing, the user is automatically logged out. As of September 2019, accounts which have not been active for at least six months will be closed.

Health professionals can also access individual Register records via the NT shared electronic health record portal (only for individuals who have consented to the NT or national shared electronic health record).

Control Program staff may also access Register data using Business Intelligence. Access to the Register data via Business Intelligence is restricted to Control Program team and IT administrators.

### **Dissemination of data for primary purposes**

Data are disseminated by the Control Program on a regular basis for operational purposes. Quarterly reports with patient level data are sent to identified health service staff including CQI staff. Quarterly reports are tabled during NT and Central Australian RHD Steering Committee meetings; data in these reports are predominantly aggregated at the regional level with some de-identified patient level information.

### **Access to data for secondary purposes**

Provision of data for secondary purposes is governed by the *NT Information Act 2002*, the *NT Information Privacy Principles (IPPs)* - specifically IPP2.1 (ca)(iv) & section 86(1)(a)(iv), the *Data Release NT Health Guideline*, and internal standard operating procedures.

## Data for research

In accordance with the NT Information Act Guideline (June 2011), information is only released for research if the following conditions are met:

- it is necessary for research, or the compilation or analysis of statistics;
- it is in the public interest;
- the research, compilation or analysis will not be published in a form that identifies the individual;
- it is impracticable for the organisation to seek the individual's consent before the use or disclosure;
- in the case of disclosure - the organisation reasonably believes the recipient of the information will not disclose the information;
- a Human Research Ethics Committee has reviewed the proposed activity and is satisfied that the public interest in the activity outweighs the public interest in maintaining the level of privacy protection provided by the Information Act.

Requests for data for research purposes are coordinated by the NT Department of Health Data Management System Reporting (DMSR) team. The data fields available for research are described in the NT RHD Register data dictionary for research (available on request from the DMSR team: [DataReleaseRequests.DoH@nt.gov.au](mailto:DataReleaseRequests.DoH@nt.gov.au)). Release of data is guided by the Data Release NT Health Guideline. The process for providing data to approved projects is governed by the Control Program's *Data release to research projects* standard operating procedure.

## Data provision to meet contractual obligations

Data are provided to the Australian Government to meet the contractual obligations of the *Rheumatic Fever Strategy* funding agreement.

## Provision of aggregated data to support community-driven RHD education or health service delivery activities (not research)

The Australian Government policy on public data is that all government agencies should make non-sensitive data open by default. It is especially important to share data about Aboriginal and Torres Strait Islander Australians with Aboriginal and Torres Strait Islander Australians.<sup>1</sup>

In recognition of the value of communities knowing their own burden of disease, relevant community based organisations (eg. health clinics, schools, local councils) may apply directly to the Data Custodian for an aggregated report on the burden of ARF/RHD in their population.

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1. Biddle, N. 2014. Data about and for Aboriginal and Torres Strait Islander Australians. Issues paper no. 10. Australian Institute of Health and Welfare.

This information will be released with the following statement:

At the request of *(to be completed by data custodian or delegate)* this information has been released by the Department of Health for a specific purpose, to inform the development of *(to be completed by data custodian or delegate)*.

NT Health Data Release Guidelines state that the collection, use and disclosure of information from which Aboriginal communities might be identified is a sensitive issue in the NT. A non-legal concept of 'community privacy' exists and has been respected in the collection and publication of health and other sensitive information about Aboriginal communities in the NT. As a matter of policy, the Department has undertaken to ensure that individual communities are not identified without their consent in Agency publications.

The data custodian responsible for data contained in the NT RHD Register has determined that in this instance the potential benefits of release of data (improvements in practice, processes, education or the public good) outweigh the need to maintain community privacy.

This information should not be used in any publications, including in mainstream media or social media, in a way which would identify an Aboriginal community without the consent of the appropriate leadership organisation of that community.”

#### Protection of patient and health service/community privacy

As per the Data Release NT Health Guideline, patient/client confidentiality, including the identity of communities and health services is maintained by adopting a variety of measures including:

- aggregation of data, for example, into large geographic areas, age groups or Indigenous status,
- suppression of counts less than five and
- suppression of data that may be easily re-identified due to unique combinations of characteristics.

## Related documents

Document name	Document availability
NT Information Act 2002	<a href="https://legislation.nt.gov.au/Legislation/INFORMATION-ACT-2002">https://legislation.nt.gov.au/Legislation/INFORMATION-ACT-2002</a>
IPP2.1(ca)(iv) & section 86(1)(a)(iv) - Information Act Guideline	<a href="https://infocomm.nt.gov.au/_data/assets/pdf_file/0008/184643/s86-Useanddisclosureofhealthinformationforwebsite.pdf">https://infocomm.nt.gov.au/_data/assets/pdf_file/0008/184643/s86-Useanddisclosureofhealthinformationforwebsite.pdf</a>
Data Release NT Health Guideline	<a href="http://internal.health.nt.gov.au/PGC/DM/Documents/GBS/Data Management/Data Release NT Health Guideline.docx">http://internal.health.nt.gov.au/PGC/DM/Documents/GBS/Data Management/Data Release NT Health Guideline.docx</a> (Internal)  Upon request from the NT DoH DMSR team ( <a href="mailto:DataReleaseRequests.DoH@nt.gov.au">DataReleaseRequests.DoH@nt.gov.au</a> )
NTRHDCP Information access policy	Upon request from the NT RHD Control Program (email: <a href="mailto:RHDDarwin.THS@nt.gov.au">RHDDarwin.THS@nt.gov.au</a> )
NT RHD Register Access Policy Statement and Application Form	<a href="https://digitallibrary.health.nt.gov.au/prodjspui/handle/10137/780">https://digitallibrary.health.nt.gov.au/prodjspui/handle/10137/780</a>
NT RHD Data Quality Statement	Upon request from the NT RHD Control Program (email: <a href="mailto:RHDDarwin.THS@nt.gov.au">RHDDarwin.THS@nt.gov.au</a> )
NT RHD Operational Data Dictionary	Internal use only
NT RHD Data Dictionary for researchers	Upon request from the NT DoH DMSR team ( <a href="mailto:DataReleaseRequests.DoH@nt.gov.au">DataReleaseRequests.DoH@nt.gov.au</a> )
Standard operating procedures: - data release to research - hospital surveillance - PCIS surveillance - Register user access - ARF cluster investigation	Internal use only