

Guidelines for Applicants

1. Introduction

Details associated with the diagnosis, treatment and management of people who have, or may have, Acute Rheumatic Fever (ARF) and/or Rheumatic Heart Disease (RHD) is reported to CHHHS by Queensland Hospital and Health Services (HHSs) under authority provided by the Director-General of Queensland Health, and by clinicians working in the community (eg GPs). This information is held by CHHHS on the state-wide RHD Register. The RHD Register is an information source available to support the care and treatment of patients; and inform the evaluation, management, monitoring and planning of health services.

The Manager and the Data Manager and Analyst of the Rheumatic Heart Disease Register and Control Program are the data custodians of information held on this register. The data custodians have authority to release information from the register, subject to approval from the Director of Tropical Public Health Services – Cairns (CHHHS).

Deidentified data from the RHD Register is regularly reported and made available by the Australian Institute of Health and Welfare. This publicly available information is aggregated at state level.

These Release of Acute Rheumatic Fever and Rheumatic Heart Disease Data – Guidelines for Applicants (Guidelines) are intended to assist persons seeking access to non-public information from the RHD Register.

2. Purpose and Scope

The release of data from the RHD Register is governed by processes which protect the privacy and confidentiality of individuals. These Guidelines describe the process by which applications can be lodged by a person (applicant) to obtain the necessary approvals that are required prior to release of data from the RHD Register by the data custodians (subject to approval by the Director of Tropical Public Health Services).

This data release process is for access to data contained on the RHD Register. For requests relating to release of data from the Notifiable Conditions Register, please refer to the Release of Data from the Communicable Disease Branch – Guidelines for Applicants available on the Queensland Health website at: https://www.health.qld.gov.au/_data/assets/pdf_file/0022/444910/data-request-form.pdf

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Additional Information and Application forms are available at:

HREC Research Ethics and Governance Information and Application:

https://www.health.qld.gov.au/hiiro/html/regu/regu_home

PHA Information and Application Form:

https://www.health.qld.gov.au/hiiro/html/regu/aces_conf_hth_info

SSA Site Specific Assessment Submission Checklist

<https://cairns-hinterland.health.qld.gov.au/research/start-a-research-project/apply-for-governance-authorisation>

3. Principles governing data provision

3.1 Confidentiality and security

As designated officers, all Queensland Health officers, employees and agents (including the data custodians of the RHD Register and the Director of Tropical Public Health Services) are subject to a strict statutory duty of confidentiality under the *Hospital and Health Boards Act 2011* (Qld) (HHBA) which, subject to certain prescribed exceptions, prohibits the release of information which could enable a person who is receiving, or has received, a public sector health service to be identified. Disclosure of data in contravention of the HHBA is an offence.

In addition, there are a number of other statutory and regulatory instruments which authorise or require access to, or disclosure of, certain information in specified circumstances, including the National Privacy Principles contained in the *Information Privacy Act 2009* (Qld) (IP Act). Non-compliance in most circumstances will constitute an offence and may attract serious penalties.

3.2 Deidentified disclosure

Aggregated and non-identifiable data that is not readily available in publications can be provided in a format that meets the applicant's needs and maintains confidentiality. Requested data may be de-identified to maintain patient confidentiality. De-identification will be assessed on a case-by-case basis but may include:

- Suppression of counts less than 10 when the denominator is less than 1,000 people.
- Suppression of data where population counts are not available or indeterminate.
- Line listed data may be aggregated by different groups demographics such as age groups, indigenous status or sex where counts are small.

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- Suppression of counts where the information is likely to be re-identifiable as they are rare and or highly sensitive.

4. Access to confidential and personal information for research

The Health Innovation, Investment and Research Officer (HIIRO) is the central point of contact for researchers seeking advice and direction on ethical and governance issues associated with the conduct of research using Queensland Health data.

Please refer to: <https://www.health.qld.gov.au/hiiro> for further information. Queries about the access to confidential health information using the Public Health Act application process should be directed to HIIRO using contact details listed on https://www.health.qld.gov.au/hiiro/html/regu/hrec_contacts

4.1 Specific guidance for access to RHD Register data

Applicants should contact the data custodians of the RHD Register prior to completing applications to be advised of any data limitations, confounders and any potential flaws in data methodology.

A number of questions arise from applicants making requests for data held on the RHD Register for research purposes, including:

- Does preparation of a conference abstract or poster constitute research?
- Do I need Human Ethics Research Committee (HREC) approval to obtain the data?
- I can already access the data in my role in Queensland Health, why do I need data custodian approval?

The answers to these questions can vary depending on a number of circumstances. As a general rule, providing non-re-identifiable data to individuals for the purpose of conferences talks, posters etc., may not require interaction with an ethics committee or chair, providing the data custodians and Director of Tropical Public Health Services are happy to release data in these circumstances. Please contact the chair of your local HREC to seek clarification on a case-by-case basis:

https://www.health.qld.gov.au/hiiro/html/regu/hrec_contacts

There are some circumstances where it is unequivocal that a full HREC review and application is required. The Communicable Disease Branch can provide clear guidance in collaboration with the Office of Health and Medical Research to guide applicants.

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For researchers within Queensland Health the use of data for routine clinical work and for research purposes sometimes overlaps. The rules governing use of confidential data are enshrined in the HHBA.

An application for access to data held on the RHD Register must be in made in writing (email or post). Application form is included in these Guidelines to help applicants set out relevant details of the confidential information sought and assist staff in locating such records.

Applications should be addressed to the RHD Register at ArfRhdRegister@health.qld.gov.au

Access to and use of register data always requires an assessment and approval to release by both data custodians and the Director of Tropical Public Health Services.

5. Data accuracy and completeness

A number of quality checks are performed to ensure that data is accurate at the time of extraction. Completeness of data varies. Caution should be used when analysing and interpreting surveillance data.

Changes in surveillance methods, diagnostic techniques and reporting practices may contribute to differences in case ascertainment over time. Data may be different to that provided in previous and/or future reports and are subject to change as a result of active case findings, ongoing data quality and cleaning activities.

Accuracy of data prior to 2001 cannot be guaranteed as this is prior to implementation of the current notifiable conditions and vaccination data collection systems.

Prior to the release of data, RHD Register and Control Program staff will liaise with the applicant to ensure data extracts meet the purpose and the applicant has been advised of any relevant limitations as well as any conditions associated with release.

5.1 Limitations of data

RHD data collection underestimates echocardiography and should not be used to estimate compliance with ARF and RHD key performance indicators. Difficulty in obtaining echocardiogram reports from multiple external data sources means that data may be incomplete.

As some people with ARF/RHD are mobile, and because of the long-term nature of the disease, the same ARF episode may be recorded in multiple state jurisdictions.

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Improved consistency in data definitions, active case findings and data quality activities have caused changes in some analyses, leading to differing results compared with previous publications. As a result of these changes, information presented in the provided data is not comparable with the content of previous reports.

Data is accurate at the time of collection but are subject to change over time if more or different information is provided about cases. Due to the long-term nature of RHD, even demographic details, such as place of treatment, can change multiple times.

6. Conditions of release of the data

The release of data will be approved only for the specific purpose stated in the request. The data custodians have the authority to approve data release with or without conditions including the right to comment on the use and interpretation of data prior to publication or to veto its use (subject to approval by the Director of Tropical Health Services).

The data shall not be shared/presented or made public in their original or manipulated form, such as publications or presentations, without explicit consent. Use of the same data set for a different purpose will require further approval from the data custodians (subject to approval by the Director of Tropical Health Services).

7. Security guidance for recipients of data

Once the data is released to you, it is required to be protected as confidential information under part 7 of the HHBA www.legislation.qld.gov.au/view/pdf/inforce/current/act-2011-032 and the IP Act www.legislation.qld.gov.au/view/pdf/inforce/current/act-2009-014.

Upon receipt of the requested data, the requestor agrees:

- Not to disclose or share the information to third parties or to another person who has no need to have such information.
- To take caution in relation to the provision of data items that pose a high risk of identification because they may be used to identify specific individual and health services.
- To use a strong password to protect the file and save it in a safe location to prevent unauthorised access of the data.

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Application form

Applicant details

Name of requesting person

Position

Agency/Institution name

Telephone Email

I have read and understood the preceding 'Guidelines for applicants' ☐ Yes ☐ No

Purpose of request *[Please attach protocols or other relevant documents]*

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.....
.....

Do you plan to publish or present the data in the public domain? ☐ Yes ☐ No

When is the data required by?.....

Data sought

Is the data required to be identified ☐ Yes ☐ No

If yes, please describe why deidentified information is not sufficient:

.....
.....

Aggregation ☐ Line Listing ☐ Counts ☐ Percentage

If counts or percentages are required, please supply detailed tables in the format required.

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Output Format to ☐ Excel ☐ PDF ☐ Other

Filters:

☐ All Active Patients ☐ ARF only ☐ RHD only ☐ On Bicillin only

Age range (Paeds, Under 15)

Date range

Regional filter/s (e.g., HHS, provider)

Any other filters to data (e.g., indigenous only)

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Fields required:

- | | | | |
|--|---|--|---|
| <input type="checkbox"/> Name | <input type="checkbox"/> Date of Birth | <input type="checkbox"/> HHS | <input type="checkbox"/> Provider/s |
| <input type="checkbox"/> Age | <input type="checkbox"/> Gender | <input type="checkbox"/> Indigenous status | <input type="checkbox"/> Ethnicity |
| <input type="checkbox"/> Prophylaxis details | <input type="checkbox"/> Bicillin adherence | <input type="checkbox"/> Echo details | <input type="checkbox"/> Echo overdue details |
| <input type="checkbox"/> Latest RHD status | <input type="checkbox"/> Latest priority | <input type="checkbox"/> Surgery counts | <input type="checkbox"/> ARF history |

Other (specify)

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Basis of request

Please identify the basis of the request for RHD Register data and attach the relevant evidence.

Select one

☐ **Research**

Has a HREC application been submitted and approved?

If yes, attach approval letter and record below: ☐ Yes ☐ No ☐ N/A

• Approval number:

• Committee:

If N/A state reason:

Has a PHA application been submitted and approved? ☐ Yes ☐ No ☐ N/A

If yes, attach approval letter and record below:

• Approval number:

If N/A state reason:

Has a Site-Specific Assessment (SSA) been submitted and authorised? ☐ Yes ☐ No ☐ N/A

If yes, attach approval letter and record below:

• Approval number:

If N/A state reason:

☐ **Care or treatment**

By selecting this option, you confirm that the information is required for the care or treatment of the person to whom the data relates.

☐ **Evaluating,
managing,
monitoring or
planning health
services**

The information is to be provided to another designated person for the purposes of evaluating, managing, monitoring or planning health services.

- Attach project plan.

☐ **Non-identifiable
data**

The data is de-identified to the extent that it could not be re-identified to identify an individual (including by linking the data with another dataset).

Please explain the reason that you consider the data to be non-identifiable:

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.....

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This application is true and correct to the best of my knowledge:

Signature Date Signed

Name

Position

QLD RHD Program Office Use Only

Request type

Prepared by Date prepared

File Location

1. The application is:

☐ approved (see (2) for the basis of release and (3) for the conditions of release)

☐ not approved (see (4) for the reasons the application is refused)

2. The **release** of data as requested above is approved on the following basis (select one):

<input type="checkbox"/> Research	HREC approval, PHA approval and SSA approval have been received and is consistent with the scope of requested data. PHA ss 282, 284; HHBA s 143; NPP 2.1(f).
<input type="checkbox"/> Care or treatment	Applicant has confirmed that data required for care or treatment of a person to whom the data relates. HHBA s 145 / NPP 2.1(a).
<input type="checkbox"/> Evaluating, managing, monitoring or planning health services	The data is being provided to another designated person. The purposes are evaluation, management, monitoring or planning health services. Project plan or other document for project has been provided with the application and is consistent with the scope of requested data. HHBA s 150 / NPP 2.1(a).

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<input type="checkbox"/> Non-identifiable data	<p>The data is de-identified to the extent that it could not be re-identified to identify an individual (including by linking the data with another dataset).</p> <p>Advice from a data scientist or statistician has been obtained if status of identifiability of data is uncertain.</p>
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3. The release of data as requested above is approved subject to the following conditions:

- The recipient will not use any RHD Register data for a purpose outside that described in this application.
- The recipient will not attempt to reidentify deidentified RHD Register data
- The recipient will not publish identifiable or re-identifiable RHD Register data
- The recipient will notify Queensland RHD Register and Control Program if a HREC approval is withdrawn
- The recipient will notify Queensland RHD Register and Control Program if it receives any complaints about its use of RHD Register data
- The recipient will immediately notify the Queensland RHD Register and Control Program if there is a known or suspected data breach involving RHD Register data
- The recipient will provide any proposed publications involving the RHD Register data to the Queensland RHD Register and Control Program at least 30 days prior to intended publication

☐ Queensland RHD Register and Control Program has a right of comment on use of data and interpretation prior to publication

☐ Queensland RHD Register and Control Program has a right of approval or veto of data and interpretation prior to publication

☐ Other conditions

Any concern with the release of the data:

.....

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4. Release of data as requester above is not approved

Reason:

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Release authorised by RHD Register and Control Program Data Manager and Analyst:

Signature Date Signed

Name

Release authorised by RHD Register and Control Program Manager:

Signature Date Signed

Name

Release approved by Director, Tropical Public Health-Cairns, CHHHS:

Signature Date Signed

Name

Position

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