

Release of Acute Rheumatic Fever and Rheumatic Heart Disease data in Queensland

15 July 2015

Guidelines for applicants

1. Introduction

The *Public Health Act 2005* (PHA) aims to protect people from the spread of communicable diseases in ways that provide a balance between protecting public health and allowing individual rights to liberty and privacy. To fulfil this aim, information about people who have, or may have, a notifiable condition must be reported to Queensland Health and is held on a notifiable conditions register. Details associated with the diagnosis, treatment and management of people with the notifiable condition, acute rheumatic fever (ARF), and those individuals who are known to have the non-communicable condition, rheumatic heart disease (RHD) and who have consented are contained on the state-wide ARF/ RHD Register.

The Senior Director of the Communicable Diseases Unit (CDU) and the Director of Tropical Public Health Services – Cairns (Cairns and Hinterland Hospital and Health Service) are the delegated data custodians of the information held on this register.

Information from this registry is regularly reported and made available in the public domain. The publicly available information is aggregated at to state level. Individuals or organisations requiring any lower level data (i.e. Hospital and Health Service level) may need to gain permission to access additional information from the register.

2. Purpose and scope

The release of ARF and RHD data by the RHD Register and Control Program is governed by processes which protect the privacy and confidentiality of individuals. This document describes the process by which applications can be lodged to obtain these data and the necessary approvals that are required prior to release of data by the custodian.

3. Principles governing data provision

Aggregated and non-identifiable data that are not readily available in the publicly available publications can be provided in a format that meets client needs and maintains confidentiality. Requested information may be de-identified to maintain patient confidentiality. De-identification may include:

- Suppression of counts less than 5 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.
- Suppression of counts where the information is likely to be reidentifiable as they are rare and or highly sensitive.

4. Access to confidential information for research

The Office of Health and Medical Research (OHMR) 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: http://www.health.qld.gov.au/ohmr/html/regu/aces_conf_hth_info.asp for further information. Queries about the access to confidential health information using the Public Health Act (PHA) application process can be emailed to hmr@health.qld.gov.au

4.1 Specific guidance for access to confidential ARF/RHD Register data

Applicants should discuss their data requirements with the Manager, RHD Register and Control Program for Queensland prior to completing applications for access to data whether the data are identifiable, potentially re-identifiable or non-reidentifiable.

A number of questions arise from applicants making requests for acute rheumatic fever and rheumatic fever data for research purposes:

- 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-reidentifiable data to individuals for the purpose of conferences talks, posters etc., do not require any interaction with an ethics committee or chair, providing the data custodian is happy to release the data in these circumstances. If there is any doubt applicants can be directed to a chair of a HREC to seek clarification on a case-by-case basis.

There are some circumstances where it is unequivocal that a full HREC review and application under the PHA is required. The CDU can provide clear guidance in collaboration with the OHMR to guide applicants.

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 *Hospital and Health Boards Act 2005*.

Access to and use of register data always requires an assessment and approval to release by both data custodians.

5. Data accuracy and completeness

A number of quality checks are performed to ensure that data are accurate at the time of extraction. Completeness of data varies across the range of notifiable conditions. 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 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.

Applicants are encouraged to discuss their data request, including any limitations of the data, with the Manager, RHD Register and Control Program for Queensland. 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.

6. Security guidance for recipients of data

The Information Privacy Principles in the Commonwealth's Privacy Act 1988 must be adhered to at all times. ***Upon receipt of the requested data, the requestor must agree to:***

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

Release of data on ARF and RHD in Queensland

RHD Register & Control Program, Queensland Health

Email ArfRhdRegister@health.qld.gov.au

Telephone: 1300 135 854

Fax: (07) 4051 4322

Data are released for the purposes stated in this application only.

Name of requesting person

Position

Agency/Institution name

Telephone Email

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

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

Purpose of request

.....

Date Requested HREC Applications submitted & approved HREC Yes No

Date Required Committee:

Approval Nubmer:

Disease/s

.....

Date range

Fields required

Sex

Indigenous status

Age, please specify what age/age range/age group is required

.....

Geographical breakdown by

.....

Other (specify)

.....

.....

Output format PDF XLS Other (specify)

Aggregated Counts Percentage Rates

Line Listing*

**Note: Line listing of identifiable or potentially re-identifiable data would require HREC and PHA, a copy or copies of the approval letter/s should be submitted*



QLD RHD Program Office Use Only

Request type

Prepared by Date prepared

File Location

Conditions of Release

- 1. The release of data as requested above is approved
- 2. The release of data as requested above is approved subject to:
 - right of comment on use of data and interpretation prior to publication
 - 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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- 3. Release of data as requested above is not approved

Reason why the data is not be released
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.....
.....

Release approved by Signature Date signed

Name

Position

Release approved by Signature Date signed

Name

Position

Date sent Date filed