Terms of Reference

## Queensland Aboriginal and Torres Strait Islander Rheumatic Heart Disease Action Plan 2018 – 2021 Data Working Group

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| Purpose |
| The aim of the Rheumatic Heart Disease Action Plan (RHD-AP) is to contribute to improving health outcomes of Aboriginal and Torres Strait Islander people living with, or at risk of, Acute Rheumatic Fever (ARF) and Rheumatic Heart Disease (RHD).  The Action Plan has 22 key actions and is guided by five priority areas that have been identified to address ARF and RHD among Aboriginal and Torres Strait Islander Queenslanders.   1. **Promote, prevent, empower**   Ensure patients have the information they need to enable them to make the best decisions on their health.   1. **Improve the patient experience**   Provide patients with a comfortable clinical experience, coordinated streamlined service delivery and positive engagement with health care providers.   1. **Strengthen the approach**   Work cohesively to establish new relationships and partnerships with health service providers and build on existing ones.   1. **Foster clinical knowledge**   Enable health professionals to appropriately prevent, diagnose and manage ARF and RHD.   1. **Enhance the Queensland RHD Register and Control Program**   Enable the Register to fully meet the needs of patients, other stakeholders and the requirements of the RFS and this Action Plan.  The Governance Committee for the Action Plan is chaired by Joy Savage, Executive Director Aboriginal and Torres Strait Island Health, Cairns and Hinterland Hospital and Health Service (CHHHS) and co-chaired by Dr Richard Gair, Director Tropical Public Health Unit, CHHHS and Dr Gregory Starmer, Director of Cardiology, CHHHS.  There are four high-level working groups providing forums for connecting key stakeholders and enabling implementation of actions which feed into the Governance Committee. The aim of this governance structure, through the sharing of expertise, is to enable a clear mechanism for effective collaboration with participating organisations and other relevant stakeholders.  This document presents an outline of the process and principles that will guide the RHD-AP Data Working Group including the membership, function and protocols that will ensure the proper governance and support is provided to the project. |

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| **Memberships** | |
| **Chair** | Project Coordinator, Queensland Aboriginal and Torres Strait Islander, Rheumatic Heart Disease Action Plan |
| **Members** | * Manager, Queensland RHD Register and Control Program * Data Manager, Queensland RHD Register and Control Program * Manager, Statistical Services, ATSIHB, Queensland Health * Director Medical Services, Wuchopperen Health Service * Program Advisor, Chronic Conditions Strategy, Apunipima Cape York Health Council * Manager, Statewide Cardiac Clinical Informatics Unit, Queensland Cardiac Outcomes Registry (QCOR) * Senior Epidemiologist, Communicable Diseases Branch, Queensland Health |
| **Proxies** | Working group members that are unable to attend meetings may provide an appropriate proxy. The proxy must be appropriately briefed prior to the meeting.  If the Chair is absent from a meeting or vacates the Chair at a meeting a member of the working group chosen by the members is to preside |
| **Quorum** | The quorum must contain at least one representative from the following organisations: Representative from the RHD Register and Control Program, Data Manager external to the RHD Register and Control Program and an Aboriginal Community Controlled Health Sector representative for the meeting to be recognised as an authorised meeting for the recommendations or resolutions to be valid. |
| **Other Participants** | The Chair may invite other individuals or groups to present to, or observe, meetings of the Data Working Group. Where agreed by the Chair, members may invite guests to attend meetings to provide expert advice and support to a specific topic raised. A guest’s attendance is limited to the duration of discussion on that specific topic.  Observers and guests do not have authority to make determinations in respect of working group deliberations. |
| **Secretariat** | Project Officer, Queensland Aboriginal and Torres Strait Islander, Rheumatic Heart Disease Action Plan |

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| Objectives |
| The objectives of the Data Working Group are to:   * Develop and implement a reporting framework for the RHD-AP * Support the development and implementation of the RHD-AP evaluation plan * Improve the interoperability between the RHD Register and Control Program and the Queensland Cardiac Outcomes Registry (QCOR) to improve reporting on patient outcomes * Use data to inform the resources required to undertake primary prevention activities in high-risk communities as per the Rheumatic Fever Strategy * Ensure ARF and RHD data is readily accessible from the RHD register and control program and Queensland Health notifiable conditions reports in order to enable:   + Data analysis including interpretation for use at point of care   + Definition of RHD-AP evaluation measures   + Reporting i.e. the annual Closing the Gap report * RHD Register and Control program data manager to maintain and improve the data surveillance system ensuring data quality including the availability and timeliness of data. * Enhance the data interface between primary health care providers and the QLD Register and Control program enabling the sharing of client information between health systems and services. * To assist with the following RHD-AP actions which have a data requirement:   + Establish a clinical referral system so that patients are referred to local environmental health services or staff.   + Develop regional service plans to support actions to prevent, treat and manage ARF and RHD among Aboriginal and Torres Strait Islander people within HHS areas.   + Ensure cardiac outreach services, including echocardiography, have a focus on supporting clients with ARF and/or RHD when providing services to rural and remote areas. |

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| Governance |
| The Working Group will provide expert advice and updates to the RHD-AP Governance Committee.  The RHD-AP Project team will provide chair and secretariat services for the working group.  **Meeting Frequency:**  It is proposed the group would meet monthly either face to face or by videoconferencewithcommunication out of session via email or telephone. Extraordinary meetings may be scheduled by the Chair of the Governance Committee if required. Evaluation Measures  * Periodic review of member attendance * Review of actions completed * Review of achievements against the purpose and objectives of the group.  Review of Terms of Reference A review of the terms of reference will be undertaken annually. |

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| Reporting relationships |
| The working group will report to the RHD-AP Governance Committee |

### Confidentiality

Members of the Data Working Group may receive information that is regarded as ‘commercial in confidence’, clinically confidential, or it may have privacy implications. Members acknowledge their responsibility to maintain confidentiality of all information that is not public domain.

### Meeting Protocols

1. **Induction & Development:** The following information is to be provided by the Secretariat and Chair to all Members prior to their first working group meeting:

* Terms of Reference which includes meeting protocols
* Advance schedule of meetings

1. **Meeting Attendance:** Members are to attend the meetings in person or by teleconference / videoconference.
2. **Behaviours and Responsibilities**

* All members exercise due diligence and act in good faith and align with the Queensland Health values of sustainability, compassion, inclusion, excellence and empowerment.
* Members are provided with timely access to information, and information is shared amongst members.
* Members review papers in advance of meetings and attend meetings.
* Full and active participation in discussions by all members is promoted.
* Constructive questioning and vigorous debate is encouraged with expressions of dissent undertaken in a harmonious and collegiate fashion.
* Members deal with each other with courtesy and respect.
* Issues are considered, decisions documented, and follow-up conducted.
* Conflicts of interest are disclosed and managed promptly.

1. **Role of Secretariat (Minute Taker)**

Arrange meetings and venues and advise Members. Call for agenda items prior to the meeting date. Liaise with Members as required. Prepare agenda and supporting papers, review and finalise with the Chair and distribute to Members prior to each meeting. Set up meeting i.e. room, equipment and teleconferencing facilities. Take minutes of meeting liaising with the Chair as required. Prepare minutes and finalise with the Chair before distributing. Maintain a record of all working group minutes, recommendations, action items, correspondence and other documentation. Follow up on actions items to ensure they are met with timelines. Maintain records of attendance.

1. **Role of Chair**

Ensure terms of reference and meeting protocols are met.

Confirm and approve content of agendas and minutes prior to distribution to working group Members. Liaise with the Secretariat during meetings and clarify/reiterate actions and decisions to be minuted before the next agenda item is addressed. Manage meetings so they are conducted in a professional, orderly and timely manner. Appoint a time keeper if required. The Chair shall also call for members to declare any real or potential conflicts of interest at the start of each working group meeting.

1. **Records**

Meeting documentation, agendas, minutes, action items and supporting papers will be filed and stored by the Secretariat electronically.

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| **Endorsed By:** |  | **Approved By:** |
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| **Chair of the Data Working Group** |  | **Chair of the RHD-AP Governance Committee** |
| <date> |  | <date> |

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| Version | Date | Prepared by | Comments |
|  | 30/10/2019 | Carly Dunstan, RHD-AP Project Officer | Approved by Michelle Rothwell |