

Pacific Islands Rheumatic Heart Disease Genetics Network

Guidelines and Information about Data Access

1. General principles

The Pacific Islands Rheumatic Heart Disease Genetics Network will consider applications for access to anonymised genotype data generated as a result of the Network activities. Access to data will be granted to qualified researchers for appropriate use. A qualified researcher refers to a scientist who is employed, or a student enrolled at, or legitimately affiliated with an academic, non-profit or government institution, or a commercial company.

The data will be deposited in the European Genotype Archive (EGA) and access will be by application to the Network Data Access Committee (NDAC). Access to data will be granted to researchers for appropriate use and will be governed by the provisions laid out in the associated informed consent for each cohort or collection, and the terms contained in the Data Access Agreement.

The Network Data Access Committee is concerned only with access to the core, anonymised, genotype data generated by this study. The only phenotypic information held by the Network is that which is implied by membership of a particular case or control group. Data will be accompanied by information on the sex, age and broad geographical region of collection/residence. The NDAC will not consider requests for more detailed phenotypic information which is held by the principal investigators for the individual case collections. Access to this data would be by arrangement with the relevant principal investigator.

Access is conditional upon availability of samples and/or data and signed agreement by the researcher(s) and the responsible employing Institution to abide by policies related to publication, data disposal, ethical approval and confidentiality.

2. Application procedure

Applicants requesting access to data from the Network will be asked to complete a basic application form and to agree to the terms and conditions laid out in the Data Access Agreement (DAA). The DAA must be signed by both the applicant and the relevant Head of Department, Head of Institute, or equivalent.

Successful applicants who have access to data will be designated “Registered Users” and will be issued with a username and password by the EGA to enable access to the database.

The NDAC will consider applications that include named collaborators, but each Institution must sign a separate Data Access Agreement. Should you wish to share the data with additional collaborators not previously approved, they must make a separate application for access to the Data.

Applicants agree to use the data for the approved purpose and project described in the application; use of the data for a new purpose or project will require a new application and approval.

The relevant forms can be found at www.rhdgenetics.net under the 'Data Access' tab.

3. Membership of Network Data Access Committee

Dr Joseph Kado, Head of Paediatrics, Fiji Ministry of Health Medical Services, Suva – Chair
Dr Tom Parks, Postdoctoral Clinical Fellow, Wellcome Trust Centre for Human Genetics, Oxford – Secretary
Dr Mariana M. Mirabel, Consultant Cardiologist Nationale de la Santé et de la Recherche Médicale, Paris
Dr Kathryn Robson, Principal Investigator, Weatherall Institute of Molecular Medicine, Oxford
Assoc. Prof. Andrew C. Steer, Consultant Paediatrician, Royal Children’s Hospital, Melbourne
Assoc. Prof. John K. Kauwe, Principal Investigator, Brigham Young University, Provo

4. Assessment Criteria

Each application will be assessed to determine if:

- it has been submitted by a qualified researcher or researchers, embedded in a recognised research institution that can provide institutional responsibility for appropriate research governance
- the project described constitutes 'biomedical research' in the context of the consent process, and is likely to be understood as such by the sample donors
- it breaches any of the ethical permissions or restrictions in the consent forms for any component cohort or collection
- it has the potential to produce information that will enable identification of individual participants
- that PhD students include details of their research supervisors

In addition the NDAC has agreed NOT attempt to peer review the scientific quality of proposals. However, it does ask for a brief summary of the research to be undertaken, in order to judge whether it falls within the scope of the consents. It also considers that grossly inadequate research is ethically questionable, and reserves the right to refer back for clarification those requests that do not appear to attain even a minimal standard of competence

5. Data Available

Please visit www.rhdgenetics.net to view the list of datasets. Individual-level genotype and sequence data will be accompanied by:

- chromosome position and strand information
- age at collection where available
- broad geographical region of residence
- sex where available