

Pacific Islands Rheumatic Heart Disease Genetics Network

Data Access Agreement

This agreement governs the terms on which access will be granted to the genotype data generated by the Pacific Islands Rheumatic Heart Disease Genetics Network.

In signing this agreement, You are agreeing to be bound by the terms and conditions of access set out in this agreement.

For the sake of clarity, the terms of access set out in this agreement apply both to the User and the User's Institution (as defined below). User Institution and User are referred to within the agreement as "You" and "Your" shall be construed accordingly.

Definitions:

Network means the Wellcome **Pacific Islands Rheumatic Heart Disease Genetics Network**, a group of clinicians and scientists at institutions across Pacific Island Nations working alongside investigators from the UK, France and Australia with the aim of using human genetics research to investigate susceptibility to rheumatic heart disease (RHD)

Data means all and any human genetic data obtained from the Network.

Data Subject means a person, who has been informed of the purpose for which the Data is held and has given his/her informed consent thereto.

User means a researcher whose User Institution has previously completed this Data Access Agreement and has received acknowledgement of its acceptance.

Publications means, without limitation, articles published in print journals, electronic journals, reviews, books, posters and other written and verbal presentations of research.

User Institution means the organisation at which the User is employed, affiliated or enrolled.

Terms and Conditions:

In signing this Agreement:

1. You agree to use the Data only for the advancement of medical research, according to the consent obtained from sample donors.
2. You agree not to use the Data for the creation of products for sale or for any commercial purpose.
3. You agree to preserve, at all times, the confidentiality of information and Data pertaining to Data Subjects. In particular, You undertake not to use, or attempt to use the Data to compromise or otherwise infringe the confidentiality of information on Data Subjects and their right to privacy.
4. You agree not to attempt to link the Data provided under this agreement to other information or archive data available for the data sets provided, even if access to that data has been formally granted to you, or it is freely available without restriction, without specific permission being sought from the relevant access committees.
5. You agree not to transfer or disclose the Data, in whole or part, or any identifiable material derived from the Data, to others, except as necessary for data/safety monitoring or

programme management. Should You wish to share the Data with a collaborator outwith the same Institution, the third party must make a separate application for access to the Data.

6. You agree to use the Data for the approved purpose and project described in your application subject to the requirements and limitations given in Schedule 1; use of the data for a new purpose or project will require a new application and approval.
7. You accept that Data will be reissued from time to time, with suitable versioning. If the reissue is at the request of sample donors and/or other ethical scrutiny, You will destroy earlier versions of the Data.
8. You agree to abide by the terms outlined in the Network 'Publications Policy' as set out in Schedule 2.
9. You agree to acknowledge in any work based in whole or part on the Data, the published paper from which the Data derives, the version of the data, and the role of the Network and the relevant primary collectors and their funders. Suitable wording is provided in the Publications Policy given in Schedule 2.
10. You accept that the Network, the original data creators, depositors or copyright holders, or the funders of the Data or any part of the Data supplied:
 - a. bear no legal responsibility for the accuracy or comprehensiveness of the Data; and
 - b. accept no liability for indirect, consequential, or incidental, damages or losses arising from use of the Data, or from the unavailability of, or break in access to, the Data for whatever reason.
11. You understand and acknowledge that the Data is protected by copyright and other intellectual property rights, and that duplication, except as reasonably required to carry out Your research with the Data, or sale of all or part of the Data on any media is not permitted.
12. You recognise that nothing in this agreement shall operate to transfer to the User Institution any intellectual property rights relating to the Data. The User Institution has the right to develop intellectual property based on comparisons with their own data.
13. You accept that this agreement will terminate immediately upon any breach of this agreement by You and You will be required to destroy any Data held.
14. You accept that it may be necessary for the Network or its appointed agent to alter the terms of this agreement from time to time in order to address new concerns. In this event, the Network or its appointed agent will contact You to inform You of any changes and You agree that Your continued use of the Data shall be dependent on the parties entering into a new version of the Agreement.
15. You agree that you will submit a report to the Network Data Access Committee, if requested, on completion of the agreed purpose. The Network Data Access Committee agrees to treat the report and all information, data, results, and conclusions contained within such report as confidential information belonging to the User Institution.
16. You accept that the Data is protected by and subject to international laws, including but not limited to the UK Data Protection Act 1998, and that You are responsible for ensuring compliance with any such applicable law. The Network Data Access Committee reserves the right to request and inspect data security and management documentation to ensure the adequacy of data protection measures in countries that have no national laws comparable to that which pertain in the EEA.
17. This agreement shall be construed, interpreted and governed by the laws of England and Wales and shall be subject to the non-exclusive jurisdiction of the English courts.

SCHEDULE 1

Dataset Description, Usage and Access Requirements

1. Array data

Two different genotyping platforms were used in the study. First the Illumina HumanCore-24 BeadChip™ (Illumina Inc., USA) was used to genotype entire collection. Second the HumanOmniExpressExome-8 BeadChip™ (Illumina Inc., USA) was used to genotype 64 individuals reporting Kanak ancestry recruited in New Caledonia whose DNA was also whole-genome sequenced at low coverage and 64 individuals reporting iTaukei ancestry recruited in Fiji. The following quality-controlled datasets have been deposited at EGA:

Dataset	Country	Platform	Samples	Phenotype	Restrictions on use	Requirements for access
RHD_FJ_HC24	Fiji	HumanCore-24	1389	Cases and controls	Use in group A streptococcal disease research only	Permission from the Fiji National Health Research Committee
RHD_FJ_OMNI	Fiji	OmniExpressExome-8	64	Cases and controls	Use in group A streptococcal disease research only	Permission from the Fiji National Health Research Committee
RHD_NC_HC24	New Caledonia	HumanCore-24	821	Cases and controls	Use in RHD research only	No further permissions required for RHD-related research
RHD_NC_HC24	New Caledonia	OmniExpressExome-8	64*	Cases and controls	Use in RHD research only	No further permissions required for RHD-related research
RHD_SA_HC24	Samoa	HumanCore-24	150 ⁺	Cases and controls	Use in RHD research only	Permission from the Samoa Ministry of Health Research Committee
OVGP_HC24	Various	HumanCore-24	937 ⁺	Controls	No restrictions on use	No further permissions required

*These individuals were also whole-genome sequenced at low-coverage. ⁺Also includes individuals with borderline rheumatic heart disease and individuals with mild non-diagnostic valvulopathy who were excluded from main study.

2. Low-coverage Sequence data

Sixty-four individuals reporting Kanak ancestry recruited in New Caledonia were whole-genome sequenced using HiSeq® 2000 (Illumina Inc., USA) technology. The following dataset has been deposited at EGA:

Dataset	Country	Technology	Samples	Phenotype	Restrictions on use	Requirements for access
RHD_NC_SEQ	New Caledonia	HiSeq 2000	64*	Cases and controls	Use in RHD research only	No further permissions required for RHD-related research

SCHEDULE 2

Publications Policy

The Network anticipates data generated from the project will be used by others to further our understanding of genetic susceptibility to rheumatic heart disease, as well as studies developing new analytical methods and understanding patterns of polymorphism.

Authors who use data from the project must acknowledge the Network using the following wording "This study makes use of data generated by the Pacific Islands Rheumatic Heart Disease Genetics Network. A full list of the investigators who contributed to the generation of the data is available from www.rhdgenetics.net. Funding for the project was provided by the he British Heart Foundation (PG/14/26/30509; www.bhf.org.uk), the Medical Research Council UK (Fellowship G1100449; www.mrc.ac.uk), and the British Medical Association (Josephine Lansdell Grant; www.bma.org.uk) and cite the relevant primary Network publication (details of which can be found at www.rhdgenetics.net).

Users should note that the Network bears no responsibility for the further analysis or interpretation of these data, over and above that published by the Network.

For and on behalf of User:

Name of Applicant(s):

Signature of Applicant(s):

Date:

For and on behalf of User Institution:

Signature of Institutional or
Administrative Authority:

Print name:

User Institution:

Date:

**WHEN SUBMITTING THIS DOCUMENT, PLEASE INCLUDE ALL PAGES OF
THE AGREEMENT WITH THIS SIGNATURE PAGE.**