

22 May 2018

Dr Judith Katzenellenbogen  
School of Population & Global Health  
University of Western Australia

Dear Dr Katzenellenbogen

**Reference:** 2018/HRE0401  
**AU/RED Ref:** HREC/18/CIPHS/15  
**Study Title:** Baseline for monitoring the burden of rheumatic heart disease in Australian jurisdictions: New South Wales component

Thank you for your correspondence dated 27 April 2018 responding to a request for further information/clarification of the above referenced study, submitted to the NSW Population & Health Services Research Ethics Committee. The Committee has reviewed your response and has agreed that the aforementioned application meets the requirements of the *National Statement on Ethical Conduct in Human Research (2007)*. This approval is for a maximum of five years from the date of this letter, after which time a renewal application will be required if the protocol has not been completed.

The Committee granted a waiver of the usual requirement of consent for the use of re-identifiable information held by NSW agencies, in line with the State Privacy Commissioner's Guidelines for Research and the Health Records and Information Privacy Act 2002 (NSW) and the Guidelines approved under Section 95A of the Privacy Act 1988.

The documents reviewed and approved include:

- Email of Response, dated 27 April 2018
- Cover Letter, dated 27 February 2018
- Human Research Ethics Application form, v1.3, submission code AU/1/2284313, dated 28 February 2018
- Combined Protocol version 2.1, dated 22 January 2018
- CHeReL Technical Feasibility Letter - 24 January 2018
- APDC Variable List
- EDDC Variable Checklist
- APDC & EDDC Data Custodian Sign Off Form, dated 3 April 2018
- COD URF Variable Checklist
- RBDM & COD URF Data Custodian Sign Off Form, dated 5 February 2018
- ANZSCTS Variable Checklist
- ANZSCTS Data Custodian Sign Off Form, dated 22 January 2018
- NCIMS Variable Checklist
- NCIMS Data Custodian Sign Off Form, dated 5 March 2018
- NSW Privacy Form
- Research team CVs
- NHMRC review letter
- AH&MRC Letter of Approval, dated 5 March 2018
- Heartkids Grant Approval Letter, dated 9 December 2016

- AHREC (SA) approval letter
- Prince Charles Hospital Human Research Ethics Committee approval letter, dated 2 December 2015
- SA HREC approval letter, dated 13 December 2016
- WA Health HREC approval letter, dated 13 June 2016
- WAAHEC approved letter, dated 13 October 2016

Approval is now valid for the following sites for unit record data:

- School of Population and Global Health, The University of Western Australia
- Telethon Kids Institute, WA
- Menzies School of Health Research, NT
- Baker Heart and Diabetes Institute, VIC
- Murdoch Children's Research Institute, VIC

Other approved sites:

- Rheumatic Heart Disease Australia, NT
- Communicable Diseases Branch, NSW Health Department
- Medical School, The University of Western Australia
- School of Allied Health, The University of Western Australia
- Queensland Department of Health, QLD
- Centre for Aboriginal Medical and Dental Health, The University of Western Australia
- South Australian Medical Research Institute SA

The NSW Population & Health Services Research Ethics Committee has been accredited by the NSW Ministry of Health to provide single ethical and scientific review of research proposals conducted within the NSW public health system.

The Committee is a joint initiative of the Cancer Institute NSW and NSW Ministry of Health. The Committee has been constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research (2007)* and relevant legislation and guidelines.

Please note that ethical approval is valid for **5 years**, conditional on the following:

- Principal investigators will immediately report anything which might warrant a review of ethical approval of the research, including unforeseen events that might affect continued ethical acceptability.
- Proposed amendments to the research proposal or conduct of the research which may affect the ethical acceptability of the research are to be provided to the NSW Population & Health Services Research Ethics Committee for review.
- The NSW Population & Health Services Research Ethics Committee will be notified giving reasons, if the research is discontinued before the expected date of completion.



- The Principal Investigator will provide a progress report to the NSW Population & Health Services Research Ethics Committee annually and at the completion of the study.

Your first progress report will be due **on 22/05/2019** and the duration of approval is until **22/05/2023**, after which time a new submission to the Ethics Committee will be required.

You are reminded that this letter constitutes '*ethical approval*' only. This research project must not commence at a site until separate authorisation from the Chief Executive or delegate of that site has been obtained. It is your responsibility to forward a copy of this letter together with any approved documents as enumerated above, to all site investigators for submission to the site's Research Governance Officer. Where relevant, copies will also need to be provided to the CHeReL and the data custodian.

For further information about the NSW Population & Health Services Research Ethics Committee, please refer to our website <https://www.cancerinstitute.org.au/Data-research/Research-ethics-committee>.

Should you have any queries about the ethical review of your research proposal, please contact ethics at [ethics@cancerinstitute.org.au](mailto:ethics@cancerinstitute.org.au).

Yours sincerely,

A handwritten signature in black ink, appearing to read 'D. M. Roder'.

Professor David Roder  
Chairperson  
NSW Population & Health Services Research Ethics Committee