



7 December 2016

Principal Researcher (as per the AHREC application form):	A/Prof. Judith Katzenellenbogen
Organisation:	Telethon Kids Institute
Via email to the Principal Researcher and Corresponding Researchers:	Judith.Katzenellenbogen@telethonkids.org.au Catalina.Lizama@telethonkids.org.au

**RE: Baseline for monitoring the burden of rheumatic heart disease in Australian jurisdictions:
South Australian component
Ref. No: 04-16-700**

Dear Judith,

Thank you for your submission requesting ethical review from the Aboriginal Health Research Ethics Committee (AHREC).

I am pleased to inform you that the application was reviewed at AHREC's meeting held on 1 December 2016 and met with support. The Committee recommended your application for full approval with the following standard conditions:

- 1) The approvals are granted based on the documentation and scope outlined by the researcher at the time of the review. AHREC must be notified of, and, approve, any changes to the study including minor or major changes to the study parameters, personnel updates and extension requests.
- 2) Where applicable, the onus of following the appropriate procedure for obtaining informed consent and protecting the well-being of a participant lies solely with researcher(s).
- 3) AHREC approvals are valid for 3 years from the date of the approval letter.
- 4) Studies aiming to involve an Aboriginal organisation, e.g. an Aboriginal Community Controlled Health Service, should adapt a partnership approach and go through a meaningful engagement process evidenced by an in-principle support letter or appropriate agreement.
 - a. This letter or agreement should clearly articulate the time, expertise and resources required to support the study.
 - b. Study timeframes and tools should be implemented with respect to the characteristics of each context engaged without an adverse impact on the quality of care and capacity of service.
 - c. The Committee recognises that this process may not always be possible to finalise ahead of the ethical review process and advises that its approval is conditional upon the consultation process occurring to the satisfaction of the Aboriginal organisations and people whose support is sought to achieve study goals.



AHREC is a sub-committee of AHCSA

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- 5) Where studies are granted approvals on the basis of the need to source ongoing advice from an established Aboriginal governance structure (e.g. Aboriginal advisory group, steering committee) or, where researchers indicated that it will be established, studies should be implemented as such. Should the ongoing monitoring of a study find that the original approval parameters were not adhered to by researchers, AHREC may further deliberate on the continued ethical acceptability of the study.
- 6) All adverse events to participants or local organisations and communities must be reported to AHREC immediately. These may include any serious or unexpected effect, unforeseen events and information that may invalidate the ethical integrity of the study.
- 7) Where possible, research participants should be supported for their time attending research activities. If the researchers will provide gift cards to incentivise participation, these should be basic cards that cannot be utilised for the purchase of alcohol or tobacco.
- 8) Research participants should be offered support for transportation to the location where research activities will take place and/or reimbursed for costs incurred e.g. parking, travel costs. This support should ideally be provided to participants up-front.
- 9) AHREC requires researchers to submit their annual reports every 1st of November throughout the approval timeframe. Final reports can be submitted at any time. Please find the reporting template at: <http://ahcsa.org.au/research-overview/ethical-review-ahrec/>

We wish you well with the study and look forward to receiving your progress reports. If you require further information, please do not hesitate to contact the Executive Officer, Dr Gokhan Ayturk, on 08 8273 7200 or email Gokhan.Ayturk@ahcsa.org.au .

Sincerely yours,
Dr Gokhan Ayturk on behalf of

Kim Morey
Chairperson, AHREC



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