A proposed methodology for engagement, informed consent, and governance for conducting genetic research with Indigenous communities: An Australian example

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BACKGROUND

STUDY OBJECTIVE: to better understand the pathogenesis (development patterns) of Rheumatic Heart Disease (RHD)

Location: 18 consenting communities across the Northern Territory of Australia

Sample: 500 Aboriginal people with RHD and 1,000 community-matched controls

Aboriginal governance

Community engagement

STAGE 1 AIM: Engage in culturally safe consultation and engagement with the Aboriginal community to ensure that issues associated with genetic research were thoroughly explored and discussed

STAGE 2 AIM: enrol 500 Aboriginal people with RHD and 1,000 community-matched controls across the NT

RESULTS & CONCLUSION

• This study demonstrates how preliminary efforts to address issues of relationship building and engagement assisted in developing community members’ genetic literacy and ensured that members understood what they were consenting to when giving permission to informed consent in the context of genetic research.
• This was critical to clarifying researchers’ responsibilities and obligations in relation to the future use of stored data and genetic samples for other research projects, and will more likely result in benefit sharing between community members and researchers.
• This study demonstrates that such sensitive research can be ethically and successfully conducted. It can inform a pathway for ongoing research in this field and contribute to the formation of guidelines for the conduct of genetic research with Aboriginal communities.

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