

Community at the heart of RHD control - the Yilpara experience

Strategies to date have been ineffective in reducing high rates of rheumatic heart disease (RHD) in Australian Aboriginal people. A remote Aboriginal community initiated a collaboration called On Track Watch to work towards elimination of RHD. Based in 'both-way learning' the aim was to co-design, implement and evaluate community-based participatory action research (CBPAR) to achieve this vision. Activities over 18 months related to understanding and addressing RHD social determinants were delivered through an accredited Certificate course adapted to meet learner and project needs. Findings from a co-designed project evaluation included the importance of valuing traditional knowledges and ways of learning such as locally meaningful metaphors to explore unfamiliar concepts; and empowerment through critical thinking and community ownership of knowledge about RHD and research. As knowledge ownership shifts so do power relations. We believe that any discomfort for institutions and non-Indigenous researchers as a result of projects deviating from expected pathways is worth the possible longer-term outcomes of proceeding in an empowering manner.

We argue that next stages of the RHD elimination strategy which must include scale-up of community leadership in research agenda-setting and implementation. We also suggest that the language of 'self-management' needs critical examination. Evidence from this project suggests a better practice would be to empower communities to support its members in need of care. In this context, we suggest that working with young people is a focus for further exploration in the future.