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Community-based participatory action research on rheumatic heart disease in an Australian Aboriginal homeland: Evaluation of the 'On track watch' project

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ABSTRACT

Strategies to date have been ineffective in reducing high rates of rheumatic heart disease (RHD) in Australian Aboriginal people; a disease caused by streptococcal infections. A remote Aboriginal community initiated a collaboration to work towards elimination of RHD. Based in 'both-way learning' (reciprocal knowledge co-creation), the aim of this study was to co-design, implement and evaluate community-based participatory action research (CBPAR) to achieve this vision. Activities related to understanding and addressing RHD social determinants were delivered through an accredited course adapted to meet learner and project needs. Theory-driven evaluation linking CBPAR to empowerment was applied. Data collection comprised focus groups, interviews, observation, and co-development and use of measurement tools such as surveys. Data analysis utilised process indicators from national guidelines for Aboriginal health research, and outcome indicators derived from the Wallerstein framework. Findings include the importance of valuing traditional knowledges and ways of learning such as locally-meaningful metaphors to explore unfamiliar concepts; empowerment through critical thinking and community ownership of knowledge about RHD and research; providing practical guidance in implementing empowering and decolonising principles / theories. Lessons learned are applicable to next stages of the RHD elimination strategy which must include scale-up of community leadership in research agenda-setting and implementation.

1. Introduction

Rheumatic heart disease (RHD) occurs at exceedingly high rates in Indigenous communities including Australian Aboriginal[1] people (Australian Institute of Health & Welfare, 2013). RHD is a consequence of childhood streptococcal ('Strep') infections (RHDAustralia (ARF/RHD writing group), 2012), driven by socioeconomic factors (Coffey, Ralph, & Krause, 2018) and is therefore a potent marker of health inequity (Manderson, Aagaard-Hansen, Allotey, Gyapong, & Sommerfeld, 2009), particularly as it is now almost entirely absent in non-Aboriginal Australian populations. The intractable nature of this disparity demonstrates the need for new strategies in remote Australian Aboriginal communities for the prevention of RHD. The main approach has been use of antibiotic prophylaxis after diagnosis of the precursor condition, rheumatic fever (RF) (Wyber et al., 2014) [Table 1]. Major limitations of this approach are that adherence to long-term antibiotics is challenging, and secondary prevention is too late for the majority of individuals with RHD whose RF episodes have been missed (RHDAustralia (ARF/RHD writing group), 2012).

A recent trial in Northern Australian Aboriginal communities showed that efforts to improve adherence to antibiotics for secondary prevention were mostly unsuccessful because of failures to engage

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[1] The terms 'Aboriginal' and 'Indigenous' are used interchangeably to refer to Australian Aboriginal and Torres Strait Islander people. It is acknowledged that there are many cultural differences between and within Aboriginal and Torres Strait Islander communities and our use of terms does not intend to disregard such differences.

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Table 1
Prevention strategies and treatments of rheumatic fever and rheumatic heart disease from the biomedical view.
Adapted from Wyber et al. (2014) and Katzenellenbogen et al. (2017).

Disease progression	Average age affected	Prevention strategies/treatment
Exposure to bacteria [Group A Streptococcus], causes sore throats and skin sores	From birth	Infection control, reduction in household crowding, poverty and malnutrition Improved access to health care
Rheumatic fever	Initial episode most common in 5-14 year olds	Treatment with antibiotics – normally monthly penicillin injections for 10 years
Rheumatic heart disease	Can begin in childhood, increases with age, incidence peaks between 25-40 years	Continued regular antibiotics for people at risk of RF recurrence
Heart failure (complication of RHD)	30% of those with RHD progress to heart failure within 5 years of diagnosis	Medical management of symptomatic RHD Open heart surgery to repair or replace valves

outwards from the clinic to community (Ralph et al., 2018). An RHD elimination framework is currently under development in Australia, which strongly acknowledges the centrality of community partnerships in this process (Telethon Kids Institute, 2017); however, this often remains elusive in health systems. Employment of Aboriginal Health Practitioners remains an exception rather than a rule, and non-Aboriginal healthcare providers are often transient (Russell et al., 2017), not always well-skilled in cultural competence (Ralph et al., 2017) or recognising RHD/RF, and underfunded for providing primary prevention/health promotion.

Failures to address Aboriginal health inequities have in part been attributed to the disempowering effects of top-down strategies (Dudgeon, Kelly, & Walker, 2010; Laliberté, 2012; Laliberté, Haswell, & Tsey, 2012; Siewert, 2017). Community-based participatory action research (CBPAR), based in social justice principles of self-determination (Campbell, Wunungmurra, & Nyomba, 2007) and empowerment, provides an opportunity for genuine partnering between community and academia (Wright & O'Connell, 2015). In this context community empowerment[2] results from strengths-based approaches that focus on activating existing power, developing abilities and critical thinking skills in order to facilitate action for change and a greater sense of control. Empowered communities "express their needs, present their concerns, devise strategies and make decisions to achieve political, social and cultural action to meet those needs" (Nutbeam, 1998: 354). Empowerment is linked to "citizen's rights to self-definition, with people's critical awareness of their social situation, with people organizing in order to achieve important goals" (Sadan, 2004: 20). CBPAR as a means to community empowerment is particularly emphasised where health disparities are the result of marginalisation, colonialism and power differences (Munns et al., 2017; Wallerstein & Duran, 2008) as there is a need to collectively gain greater influence, agency and control over the political/economic/social determinants of health (Kickbusch, 1998). CBPAR can also be considered a healing or restorative process as participants "gain control, become strong, and find their voice to participate in change for a strong community" (Laliberté, Haswell-Elkins, & Reilly, 2009: 66; Dudgeon, Scrine, Cox, & Walker, 2017).

In the context of RHD, we hoped that the empowering potential of community-based action research and the development of genuine partnerships would be the basis for effective chronic disease care, and prevention at the primordial and primary levels (Katzenellenbogen et al., 2017; Smith, Kirkham, Gunabarra, Bokmakarray, & Burgess, 2018). Success with such efforts has potentially broad-reaching benefits in reducing adverse outcomes of childhood infection, beyond RHD alone. Therefore, our aim was to co-design, implement and evaluate a CBPAR project on RHD prevention in a remote Aboriginal community in Australia's Northern Territory, where RHD prevalence is very high. We describe the processes, outcomes, and learnings that emerged through close adherence to the empowering principles embedded in CBPAR.

2. Methods

2.1. Study design

We report here on a theory-based evaluative study of a CBPAR project. Based in critical social theory, emancipatory CBPAR (Wallerstein & Duran, 2008) emerged in the field of community development, and emphasises the rights and capacity of those previously seen as research subjects to fully participate in research decisions and analysis, and engage in critical thinking as research collaborators or co-learners (Israel, Schulz, Parker, & Becker, 2008). Beginning by identifying the community's concerns, the action research cycles of reflection, planning, acting, further observing and reflection, then implementing new plans and action (Lewin, 1946) allows investigators to engage collectively in thinking critically about the research question to generate knowledge and practice that is of benefit to all. Common CBPAR aims include "promoting social change; guiding partnerships across sites; generating instrumental and practical knowledge; increasing focus on process (as compared with pre-designated tangible outcomes); and power sharing between the researcher and community" (Viswanathan et al., 2004:6). As a decolonising and empowering methodology (Baum, 2016; Minkler & Wallerstein, 2008:405; Freire, 1970; Wright & O'Connell, 2015) a key feature of CBPAR is to pay critical attention to power dynamics; requiring all researchers to accept a position of openness, equality, and reflexivity (Bettez, 2015).

Any evaluation of a CBPAR project must therefore include an assessment of the quality of collaboration and shifts in power dynamics (Ward et al., 2018). While CBPAR suggests that project evaluation frameworks are included as part of the co-design processes there is a tension between principles and pragmatics (Scougall, 2006). That is, while our project emphasised Aboriginal ways of knowing, being and doing, we also needed to attend to the requirements of academic publishing and readership in order to bring our findings into the biomedical 'mainstream'. As a consequence a theory-driven evaluation was applied to this project (Chen, 2012), using process and outcome evaluation frameworks described below. This approach provides a 'theory of change', promoting understanding not just of the extent to which intended outcomes were achieved, but also the mechanisms (the how and why, or why not) (Davidoff, Dixon-Woods, Leviton, & Michie, 2015). Use of theory also gives methodological rigour, contributing to the generalisability and transferability of evaluation results (Chen, 2012, cited in Kelaher et al., 2018:2). Here the overarching theory of the empowering potential of CBPAR (Freire, 1970; Tsey et al., 2007; Wallerstein & Duran, 2008) is integrated with Aboriginal research

[2] A distinction is made between individual and community empowerment. Individual empowerment refers primarily to an individual's ability to make decisions and have control over their personal life. In the context of self-management the rhetoric of 'empowerment' has often been co-opted as a means to encourage compliance (Powers, 2003) where critical thinking is replaced with self-reflection, and empowerment is an action that can be performed by a health professional on individual patients.

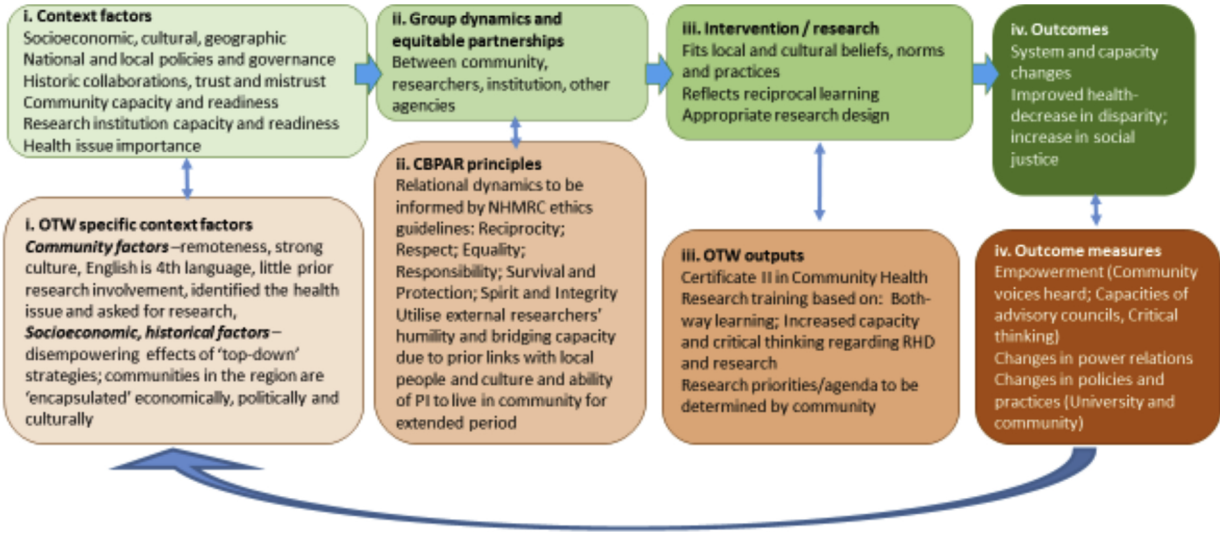

Fig. 1. OTW conceptual logic model based on Wallerstein et al. (2008).
Legend: Top level boxes are generic descriptions of logic model components. Second level boxes articulate OTW specific considerations. The large arrow represents the potential for social justice and health equity outputs to influence determining contextual factors.

principles (Kelaher et al., 2018; Wright, 2011) to provide the foundation for the study design. Decolonising theory (an intentional response taken by researchers to respond to the damages brought about by colonisation in a constructive way) (Smith, 1999; Nakata, Nakata, Keech, & Bolt, 2012), and standpoint theory (a theory that recognises and prioritises the perspectives and voices of marginalised and/or oppressed peoples to create more objective accounts of the world from their standpoint) (Guenther, Osborne, Arnott, & McRae-Williams, 2017; Lucero et al., 2018), further informed data collection and analysis. See Fig. 1 for the project program logic described in more detail.

2.2. Setting

The majority of the project was undertaken from October 2016 - December 2017 in a small, very remote Aboriginal community in North East Arnhem Land, where an estimated 15% of the population have RF or RHD (Mitchell, 2017), well above what would be expected. Here, remoteness is defined according to the Australian Bureau of Statistics, although we note that remoteness can be subjective and considered a 'metro-centric construct' (Guenther, Bat et al., 2017: 43). The community was established in 1974 as part of the homelands movement (McDermott, Dea, Rowley, Knight, & Burgess, 1998), and is one of 30 small communities in a region linked by common languages (Yolŋu matha) and cultural identity that govern how clan groups relate to each other (Morphy & Morphy, 2013). The homeland has locally-appointed and trained Community Health Workers, and a small modern clinic which is visited for 1–2 days per week by the homeland support services clinical staff (nurse and/or doctor). Traditional culture and Aboriginal languages remain strong in this region and there is limited conceptual knowledge of research as a western academic activity among the population due to limited exposure.

2.3. How the research topic arose

When the community leader became aware of the scale of RHD in his homeland (Mitchell, 2017) he determined it was his responsibility to act to ensure his people's long-term presence as carers of their country. He specified that the local school council, of which he was the chairman, would direct this task. He agreed for outside researchers to work with the school councillors who decided to call the project 'On Track Watch' (OTW). This name reflected their desire to keep young people on track with their monthly penicillin injections as well as watching out for, and preventing new cases of RF. In response, the institutional research group proposed the use of CBPAR methods for OTW, with the goals of fostering RF/RHD health literacy and seeking practical ways to prevent RF/RHD in the community.

2.4. Participants

We use the term 'facilitators' to describe external researchers and trainers, and community researchers (CRs) to define the Aboriginal residents in the homeland as co-researchers, co-authors and co-facilitators, as well as trainees. While OTW emphasised Yolŋu ways of knowing being and doing, this article has been primarily written by facilitators to meet the requirements of an academic publication and readership in attempt to influence policy makers. We use "we" throughout the article to refer to all co-authors, but where appropriate statements/quotes have been identified as the words of the community researcher co-authors (CRs), and a less academic and more active voice has been used. Other forms of publication relevant to CRs' desired ways of telling stories, and relevant to their needs such as creating local employment are in preparation, including a website and health promoting booklets.

During OTW a facilitator (E.H.) lived in the community for 15 months, mentored by a local community researcher (M.M.) and a non-Aboriginal researcher, clinician and speaker of one dialect of the Yolŋu languages (A.G.M.), with the support of the local health service. The capacity of the external researchers to position themselves as learners as well as facilitators was built on A.G.M.'s prior experience with the language group and in participatory health education founded on the work of Freire (Trudgen, 2000). This approach values Indigenous knowledge systems and the reciprocal co-creation of knowledge, which the collective researcher group termed 'both-way learning' (Herbert, 2000), also referred to elsewhere as 'two-way learning' (Purdie, Milgate, & Bell, 2011) or *Ganma* in the Yolŋu education context (Corn, 2014; Kemmis, McTaggart, & Nixon, 2013). The external researchers' commitment to cultural humility (Ward et al., 2018) and critical self-reflection was key to building trust and a sense of equity in partnerships that were inclusive of Yolŋu values.

The CRs were multilingual in regional Aboriginal languages and spoke English with varying levels of competence. Most CRs had completed year 10–12 and seven had other vocational education training (VET) qualifications relating to their employment. All CR's had personal experience of RF or RHD; two had RHD and others had close relatives

affected such as a child or parent, and sometimes both. Many CRs had other roles in the community such as teacher's aide, ranger, community health worker, employment program worker, youth worker and school janitor. Participation in the training was dependent on their ability to fit it in around work commitments and so had differing degrees of participation. Two CRs are authors of this paper and are continuing to develop research skills by collaborating on further RHD research.

2.5. Study processes and formalisation of training

A means of formalising the engagement of community members in project delivery was to invite their enrolment in an accredited course, the 10513NAT Certificate II in Community Health Research (henceforth Cert II) offered by the host research institute in partnership with the regional university as part of its commitment to capacity building and reciprocity. This was at no cost to the learner. The practical on-the-job competency-based course required learners to participate in all parts of a research project using participatory action research processes in a primary health care context. Teaching and assessment techniques were culturally sensitive and did not rely on written English responses but used oral assessments, observation checklists, group and individual discussions and the collection of a portfolio of evidence or workshop and research outputs. Content was adapted to the learning objectives of community health research projects in accordance with VET requirements. Four community based training workshops were held and ongoing training and mentoring in the community was provided by E.H. and the other authors over 24 months. M.M. was both an enrolled learner and a community facilitator to guide the learning design and implementation. Training activities included: a both ways 'unpacking' of key underpinning concepts resulting in a glossary of key terms, focus groups regarding community understandings of streptococcal infections; lived experience of RHD interviews; a 'Throat Swabbing Day'; a community audit of water and household washing hardware; and the creation and implementation of two evaluative tools (see data collection and analysis sections for further details). Broader topics such as qualitative and quantitative research methods, ethics, consent and knowledge translation, were embedded within these activities (Kickett-Tucker, Bessarab, Coffin, & Wright, 2017).

From the start of OTW, the community members articulated their priority research areas as improving nutrition; watching out for 'Strep' infection, and 'understanding teenagers'. Nutrition was relevant since the supply of fresh foods available in the local store was limited. Watching for 'Strep' infections meant being alert to the symptoms of sore throat or skin sores which can lead to RF. 'Understanding teenagers' was meant broadly but included a focus on how to help teenagers (with RF and RHD) engage in health care, including adherence to medication. Activities to address these were built into the training activities (see Table 2 for further details).

2.6. Data collection

Throughout the project we collected data through facilitators' participant observations contained in reflective journal writings, CRs group discussions, and focus groups conducted by the CRs with other community members (Ward et al., 2018). The 'Throat Swabbing Day' was a training opportunity to share knowledge of streptococcal infection, develop skills and practice gaining informed consent, data documentation and use of a point-of-care (immediate swab result) test for detection of streptococcus. The outcomes and experience of participation in this exercise were documented in a report prepared by the CRs based on focus group discussions and observational data.

Data collection tools generated collaboratively towards the end of the project included a 'Most Important Learnings' voting matrix and a Likert scale survey with additional open-ended questions. The voting matrix was developed in a group 'brainstorming' session in which ten CRs nominated and then voted preferentially for what each thought was their 'Most Important Learnings' (each had 6 votes) from OTW. Later the findings were analysed with the facilitator and six CRs. The survey was a 3-point Likert-scale survey in which CRs indicated the degree to which they felt the project processes adhered to six National Health and Medical Research Council (NHMRC)-based principles, using emoticons (sad, neutral, happy). Open-ended questions allowed further discussion of each principle (hereafter referred to as 'the emoticon survey'). Finally, illustrations of local metaphors with local language descriptions created by the CR and photographs were also collected as data (See Fig. 2 and Fig. 3).

Of these data collection methods, three were specifically designed to collect evaluative data: the 'Most Important Learnings' voting matrix, the emoticon survey and a CRs focus group to evaluate the 'Throat Swabbing Day'. The remaining data were collected during the training activities.

2.7. Data analysis

Data analysis was carried out iteratively, and involved different researcher combinations. During the project, the community-based facilitator and the CRs analysed the data collected in the 'Most Important Learnings' voting matrix, the emoticon survey and the Throat Swabbing Day results through the use of interpretive focus groups to identify themes (Redman-Maclaren & Mills, 2015) and simple quantitative data analysis. Towards the end of the project, further analysis and synthesis was carried out by E.H. and A.G.M. to align findings with the evaluation framework. Project meetings were held to discuss, confirm and edit evaluation findings with the CRs. Finally, all findings were presented back to the small community.

2.8. Evaluation frameworks

We used two evaluation frameworks grounded in decolonising and empowering theories to assess process and outcome indicators. The 'Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research' (National Health & Medical Research Council, 2003) and accompanying 'how-to' guide (National Health Medical Research Council, 2006), were used as process indicators. The outcome indicators framework used here was derived from the work of Wallerstein et al. (Wallerstein & Duran, 2010).

2.8.1. Process indicators

The NHMRC Values and Ethics guidelines evolved as part of a movement to decolonise Australian research, and seek to ensure Aboriginal inclusion in all aspects of research (including prioritisation, design, execution and evaluation) and respect for Indigenous knowledges and ways of working (Dudgeon et al., 2010). The guidelines describe six principles: Reciprocity; Respect; Equality; Responsibility; Survival and Protection; Spirit and Integrity (henceforth 'the Principles'). Despite the fact that key national Aboriginal health research bodies advocate for consistent adherence to principles such as those recommended by the NHMRC (Kelaher et al., 2018: 24, Tsey et al., 2016), there are only a limited examples where researchers have reflected on applying the Principles in practice (see, for examples, Gwynn et al., 2015 and Lehmann et al., 2008). For the OTW evaluation the Principles (including the criteria given in the guidelines regarding the successful application of each principle to Aboriginal health research) were used as an analytic framework to assess the project's implementation (Table 5).

2.8.2. Outcome indicators

A conceptual logic model to guide the outcomes evaluation was created based on that developed by Wallerstein and colleagues (Wallerstein & Duran, 2010) which links empowerment outcomes, such as activating existing power and developing critical thinking skills, to processes that closely match the NHMRC principles described above.

Table 2
Main activities undertaken in On Track Watch Cert II training.

Activity	Purpose	Outcomes	Learnings
School lunch program - set up as an employment program activity to prepare lunches for children who attended school	- demonstrate nutritious and inexpensive home-made meals - provide a sub project for OTW participants to evaluate - provide facilitator with an initial and tangible 'hands-on' task for engaging community	- meals were prepared for school children and their families to share - cost per meal was calculated as $2.00 - built trust in facilitator as responsive to community needs	- sustainability an issue - cultural preference for sharing meals - inclusive cultural practices around sharing food with the whole community - community appreciated the partnerships formed around social issues - promoted discussion of the 'money story' for food supply in the community
Community throat swabbing day (in partnership with the homeland health service)	- provide education about the presence of streptococcus germs in the throat - provide an opportunity to practice informed consent processes - opportunity to test a point-of-care swab test kit	−38 community members participated out of approximately 80 present in the community that day. 10 children had swabs collected. - OTW group developed processes for gaining consent - all participants expressed an increased understanding about the presence of Strep	- the process of gaining informed consent in this setting was group-aligned rather than individually-aligned (information was provided in a group setting, not one-on-one) - the concept of finding a germ in the throat through the process of a swab test was valuable in understanding ARF causation - community valuing of team work and partnerships
Outreach to a related homeland targeting teenagers - involved watching the "Take heart" documentary (Moonshine Agency Pty Ltd, 2016), discussing it and drawing t-shirt designs to deliver key messages (in partnership with a regional school retention program)	- fulfil culturally-based desire to spread important information to related Yolŋu clan groups	- teenagers naturally assumed the supervision of teaching younger children by reiterating information about rheumatic fever from the documentary and other resources	- value of partnerships - teenagers are well placed to deliver health education messages to younger children - health messaging from local participants were all strength-based

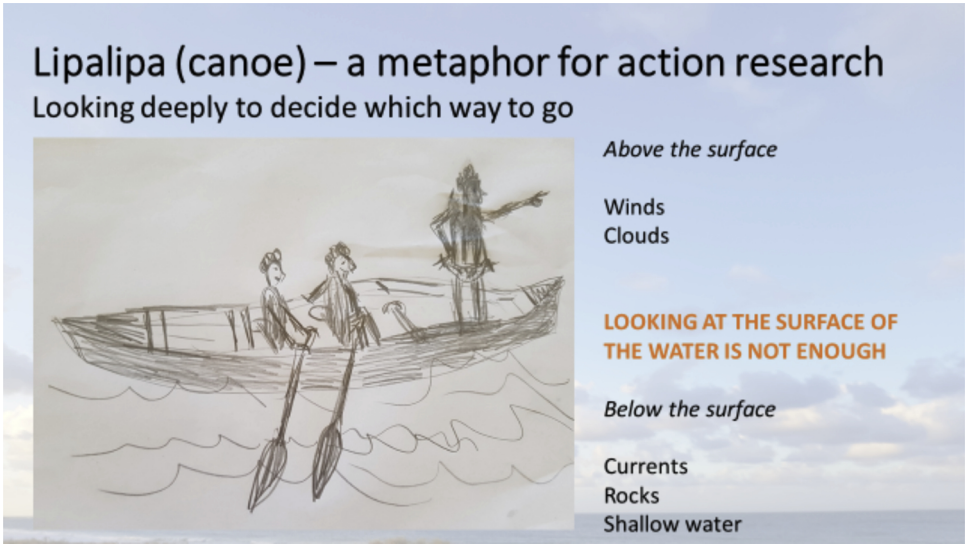

Fig. 2. *Lipalipa* (canoe) – a metaphor for action research: looking deeply to decide which way to go.
Legend: Above the surface are the winds and clouds. Below the surface are currents, rocks, shallow water. Looking at the surface of the water is not enough.

Further, Wallerstein's work has been referenced by Indigenous researchers such as Bainbridge (2009) and Tsey et al. (2007) in the context of defining empowerment and has demonstrated validity in this context having been usefully applied in conjunction with Indigenous transformative theory (Lucero et al., 2018). Additionally, empirical testing demonstrated the potential of the model to achieve health equity (Oetzel et al., 2018: c11).

Wallerstein provides five outcome domains by which success of CBPAR projects can be assessed: 1. Changes in policies and practices; 2. Culturally-based and sustainable interventions; 3. Cultural revitalisation and renewal; 4. Empowerment (demonstrated by: Community voices heard; Capacities of advisory councils (improved); and Critical thinking); and 5. Changes in power relations. In this 18-month project, reflecting the project context, we chose to focus on domains 1, 4 and 5, acknowledging that sustainable interventions (2) and cultural renewal (3) are only identifiable over a longer period. Domains 1, 4 and 5 were used as coding categories to analyse the data. The term 'critical thinking' is preferred to 'increased knowledge' (a more conventional outcome indicator in health education projects) (Freire, 1974). Critical thinking, the ability to deeply question, analyse, reflect and problem solve, is developed through the reciprocal process of co-creating knowledge (both-way learning) about the circumstances and nature of social problems, ideally produces action for change and is a key empowerment skill.

2.9. Approvals

Written approval was received from the Aboriginal elders of the community, the local Health Service, the Northern Territory Government Department of Education and the Health Research Ethics Committee (HREC) of the Northern Territory Department of Health and Menzies School of Health Research (HREC-2016-2601). Amendments to the project which developed as a result of the CBPAR process were also approved by the HREC. The CRs and community leaders also provided

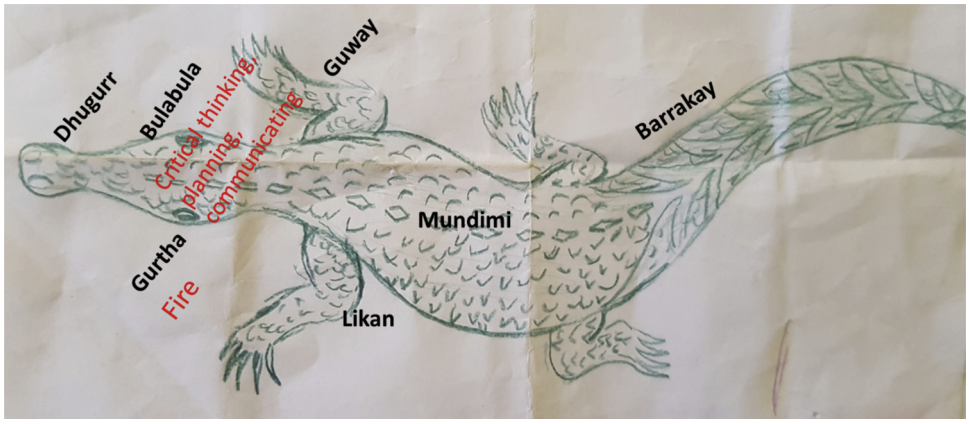

Fig. 3. *Baru* (crocodile) – a metaphor for knowledge systems.
Legend: ***Gurtha*** (the eye) is the same word as fire – the *baru's* sharp eyesight is about thinking critically, ***Bulabula*** (the head) –using the knowledge of the baru can make a person speak positive things, solve problems, be good at communicating and planning.

their endorsement by revealing some components of traditional knowledge along with translations of concepts into their language.

3. Results

3.1. Training processes and outcomes

Over 18 months, 16 adult CRs (7 males and 9 females; age range between early 20 s and 59) participated in the Cert II training. Main activities undertaken are summarised in Table 2. Eleven CRs completed the Cert II and four statements of attainment for units of competency were issued. These are considered high retention rates in this region where, in general, there are very low completion rates for Cert II training (Guenther, Bat et al., 2017). This can be seen as evidence of the benefit of using empowering and transformative learning processes where the emphasis is placed on understanding underlying concepts, valuing cultural knowledge and learning through participation in research projects. The training model allowed the project to combine 'hands on' action research (see Table 2 for examples) with relevant training and both-way learning principles (Freire, 1970) (see Table 3 for the range of learnings identified by Cert II participants). The Cert II provided the opportunity for CRs to demonstrate an understanding of a variety of western academic research tools. To be respectful of Yolŋu preferences the evaluation recognised observational processes as an equally legitimate source of knowledge in addition to surveys and focus groups. Findings from the training activities inform the following sections and results tables.

Table 3
'Most important learnings' identified by CRs.

Learning	Number of votes
Wellbeing	7
Emails, internet, typing	7
Cooking	6
Strep A	6
Learning complex words	6
Writing	6
Both-way learning	5
Media	5
Problem-plan-do-review cycle	3
Feeling confident about understanding RHD	3
Feeling confident about consent	3
Learning to explain RHD	3
Research skills	2
Feeling confident about research	2
Partnerships	1

3.2. Process indicators

Quantitative and qualitative findings related to OTW implementation processes are reported in this section. The quantitative emoticon survey results showing the extent to which CRs felt that OTW aligned with the Principles are shown in Table 4. Processes were found to align closely with the Principles overall, but some items were assigned a 'neutral' response by the CRs, especially the principle of 'responsibility' (Table 4).

An analysis of the qualitative data according to alignment with the NHMRC Principles is presented in Table 5. Illustrative quotes from CRs are included. As expression in a second language may hide depth of meaning, during coding, facilitators drew on their cultural knowledge and experiences throughout the OTW project to elaborate on what the intended meanings were, and later confirmed these with the CR co-authors. In preparing the survey the CRs' process of translating the abstract concepts embedded in the Principles into local languages required intense interrogation as the underlying principle was often not directly translatable to Yolŋu concepts. For example, because responsibility is a fundamental Yolŋu value in relation to family and community, it was challenging to translate as the term would not usually require defining. Despite these data analysis complexities, evidence of a good alignment between project processes and the Principles was found. Challenges arising from adherence to the Principles for both CRs and Facilitators are discussed below. Additionally, this more nuanced qualitative data gives greater depth and understanding of the practicalities of implementing the Principles (Table 5).

3.2.1. Challenges arising from adhering to the Principles

Specific challenges experienced during the project included those arising due to contrasting cultural approaches and values, and the need

Table 4
Emoticon survey results.

	Unhappy ☹	Neutral 😐	Happy ☺
Reciprocity	0	0	8
Respect	0	2	6
Equality	0	3	4
Responsibility	0	5	2
Survival & Protection	0	3	5
Spirit & Integrity	0	3	4

Table 5
Alignment of project processes with NHMRC Principles.

1.Reciprocity Our way of shared responsibility and obligation is based on our diverse kinship networks. This process in our communities keeps our ways of living and family relationships strong. These responsibilities also extend to the care of the land, animals and country and involve sharing benefits from the air, land and sea, redistribution of income, and sharing food and housing.	
Criteria for demonstration of alignment with principle	Evidence from OTW of alignment with principle
Project linked to community and national health priorities and contributes to health and wellbeing of participants and communities.	Community members expressed their desire to know more about, and to find actions to prevent, RHD: "We don't want our kids to have heart surgery" (CR) "we want to keep the kids healthy, community healthy, look after our land" (CR).
Institutional researchers demonstrated willingness to modify research in accordance with community values and aspirations.	Originally proposed research action areas were modified by community. Issues deemed as priorities for research and action were broadened to areas such as nutrition.
The research enhanced community capacity to benefit beyond the project, e.g. through the development of skills and knowledge.	Immediate benefit was achieved with opportunities for CRs to learn new practical skills as well as grow in critical thinking. CRs reported benefit of learning skills and knowledge. Further opportunities for trainees to benefit beyond the project have included addressing national RHD workshops, connecting to other Aboriginal researchers, developing their own resources and taking OTW to nearby communities, and employment on a new separate project (5 CRs).
2. Respect Respect for each other's dignity and individual ways of living is the basis of how Aboriginal and Torres Strait Islander peoples live. Within our cultures, respect strengthens dignity, and dignity strengthens respect. A respectful relationship encourages trust and co-operation. Strong culture is built on respect and trust, and a strong culture encourages dignity and recognition, and provides a caring and sharing environment.	
Criteria for demonstration of alignment with principle	Evidence from OTW of alignment with principle
Demonstrated respect for the way decisions are made in the Aboriginal community.	Accepting a greater number of Cert II CRs than initially anticipated. The number reflected the diversity of reasons why people came to training, including that some joined to provide leadership for the research group and some were 'sent' by elders to make the most of an opportunity for leadership development.
The research minimised the effects of difference blindness on and in the research process and engaged with Aboriginal peoples' knowledge and experience.	CR analysis of the Principles survey - "Show respect in how we work together "the right way" Use of metaphors (in themselves metaphors are the basis of Yolŋu knowledge) as the essential component of the both-way learning process.
Recognition of Aboriginal intellectual and cultural property.	Metaphors drawn from cultural knowledge, e.g. the *baru* (crocodile), the *lipalipa* provided by participants and acknowledged in all presentations/writings as such and CRs included as co-authors and co-presenters.
Processes of reaching agreement (*about the way we work together*) demonstrated engagement with the values and processes of participating communities.	Researchers fitted in with day to day community processes that impacted classes, for instance needing to attend a 'hearing ceremony' (announcement of a person's passing) and behave respectfully on hearing of a person's death.
Data, confidentiality and publication arrangements protect individual and community identity.	Confidentiality extensively discussed during OTW research training, for example during focus groups and Throat Swabbing Day.
3. Equality Aboriginal and Torres Strait Islander peoples recognise the equal value of all individuals. One of the ways that this is shown is in our commitment to fairness and justice. Equality affirms and recognises the right of Aboriginal and Torres Strait Islander peoples to be different.	
Criteria for demonstration of alignment with principle	Evidence from OTW of alignment with principle
Community is included in research processes and Indigenous and non-Indigenous knowledges are equally valued.	Both-way learning was valued especially with use of local metaphors to increasing local and Institutional understandings. "Yolŋu and Balanda combine, sharing knowledge together, talking together, sharing ideas…learning about Balanda law, culture, modern world" (CR). CRs developed their own tools for evaluating the project as a whole (see Tables 3 and 4 above) and throughout the project they analysed and reported on the data. (See also Figures 2 and 3).
The research agreements had the strength necessary to sustain equality.	The research ideas came from the community rather than from institutional researchers, the selected three action areas were significant as the basis of the project and were readily accepted because of their relevance to the community.

(*continued on next page*)

Table 5 (*continued*)

Participating communities understand and expressed satisfaction with the research, its potential benefits and distribution.	CRs' responses to a specific question about equality - 7 people said "good"; for 4 people this was about working in a group – helping, encouraging each other, "gave me understanding about how to work in a group". "It was interesting work", "good training", "learning about planning was good" (CRs).
4. Responsibility Aboriginal communities recognise the same most important (core) responsibilities involving country, kinship bonds, caring for others, and the maintenance of cultural and spiritual awareness. The main responsibility is to do no harm to any person, or any place. Sometimes these responsibilities may be shared so that others may also be held accountable.	
Criteria for demonstration of alignment with principle	**Evidence from OTW of alignment with principle**
There is transparency in the exchange of ideas and in negotiations about the purpose, methodology, conduct, dissemination of results and potential outcomes/benefits of research.	During the Throat Swabbing Day, care and responsibility for others was demonstrated in allowing community members to decide without coercion whether to participate or not; "At the school we talked to the whole group of parents and children and they felt comfortable and interested when they heard the story. People were very interested, they listened quietly" (CR). "We told them about the numbers of people with RF and RHD in the community; we explained about the Strep germ" - CR explaining the process of learning about informed consent. Community leader's statement that if he didn't do something there would be no one left to look after the land in the future is evidence of the purpose of the research originating from the community. CRs acted appropriately according to their cultural mores.
Provision was made for ongoing advice and review from community.	*Lipalipa* (canoe) action research metaphor (Figure 2) creates transparency and includes idea of ongoing feedback The evaluation of processes reported on here is evidence of accountability. Feedback using reflective processes was also undertaken at the end of the Throat Swabbing Day. We believe the course was 'audited' by a senior community member who was there to provide feedback to the community leader. He was also able to help with complex translations and ensure respect for cultural protocols.
There was clarity about the demand on partners created by the proposed research and the potential implications for partners arising from it.	Facilitators endeavoured to negotiate release time with other organisations who employed the CRs as well as remuneration for lost wages while participating in the Cert II workshops. Workshops were fitted around other commitments of CRs.
5. Survival & Protection We continue to protect our Aboriginal and Torres Strait Islander cultures, languages and identity. Recognition of our shared cultural identity, which is based on our shared values, is a significant strength.	
Criteria for demonstration of alignment with principle	**Evidence from OTW of alignment with principle**
Contributes to the social and cultural bonds among and between Aboriginal families and communities.	16 people from community were accepted to be enrolled despite the original project plan for only four CRs; no one was excluded. Everyone had either their own RHD experience or close family members meaning there was high interest.
Safeguards were in place against the research project contributing to discrimination or derision of Aboriginal individuals or cultures.	Facilitators' openness and cultural respect demonstrated by acceptance of and willingness to use two-way learning.
Respected the intrinsic values based expectations and identity of Aboriginal peoples and communities, including the balance between collective and individual identity.	Facilitators supported stated desire to "Start from our community and work our way outside to help other Homeland communities" (CR). Facilitators respect for working collectively meant accepting that CRs formed small working groups according to natural cultural constructs. But in the Cert II assessments they were recorded individually.
Research contributed to the opportunity for Aboriginal peoples to better advocate for or enjoy their cultural distinctiveness.	Extensive time was spent on translation into the local language to develop clear conceptual understandings of RHD. This included asking elders for language terms to describe research concepts such as 'respect', strengthening intergenerational knowledge of traditional language. This ensures survival, protection and value of Aboriginal languages which safeguards identities and culture. CRs' cultural metaphors were valued and they were given opportunity to present to the 'institution' using those metaphors.

Legend: Definitions under each NHMRC principle are from "Keeping research on track" (NHMRC, 2006), the companion resource to the NHMRC guidelines created for Indigenous communities, edited for conciseness, and in some cases for clarity. CR: community researcher; Balanda: white people; RF: rheumatic fever; RHD: rheumatic heart disease; OTW: On Track Watch; Yolŋu: Aboriginal language group, dialects of which are spoken at the study site. Quotes have been attributed to CRs (CR) as a group, not individually, in keeping with community values.

for all participants to constantly reflect and negotiate across cultures. These are reported below, first as challenges for community researchers and secondly for facilitators.

3.2.1.1. Challenges for community researchers. CRs experienced challenges arising from contrasting cultural approaches, for example the differences between non-Aboriginal bureaucratic/institutional processes, such as employment structures and wage disbursement, and local community attitudes to work and money that are inherently based on kinship. In this instance, institutional requirements to pay employment wages to individuals, rather than to a communal fund, was upheld. This required the CRs to work around what appeared to them as unfair and a non-recognition of true values. This typifies the pervasive effects of colonial power dynamics, even in a project seeking to be highly responsive to community needs.

Critical thinking on the research topic generated new questions that were not necessarily able to be addressed within the life of the project. For example, one CR, on learning about the importance of the specific streptococcus germ, requested that a scientist visit to tell them about all germs and the diseases they cause. Institutional power (in the sense of controlling knowledge) was retained as these requests were not able to be actioned. Similarly, as a result of the increased capacity and confidence of the community members as researchers, a desire was expressed to expand their understanding and experiences of research, such as meeting other Aboriginal researchers or starting their own projects and to be employed as researchers. This could only be supported to a small degree during the time of the project.

CRs expressed further challenges, articulated as “sometimes my feeling is not right” and “balancing was difficult” and “we want to balance the time for the next project”. A sense of inadequacy and frustration was expressed in the statement: “this is difficult sometimes when it is hard to communicate”. Further comments revealed challenges such as: having other work to do, being tired or busy, and feeling there was “too much time spent talking and not enough time doing”.

At times, interpersonal relationships were challenged Yolŋu to Yolŋu: “there is a risk, some see the reason for the research others don’t – this can get between people – we need to remind ourselves why we are doing the research”. Similarly, CRs who took on additional research work in remote (to them) capital cities, or opportunities to attend conferences, were concerned that others might misinterpret their involvement as being for personal gain. CRs expressed the necessity for good communication and understanding so that other community members realised that the researchers were not ‘*walŋa-rurraŋ’thun*’ – [literally looking into peoples’ private lives and thus causing conflict]. Cultural demands also impacted on CRs’ capacity to join the training; participation in cultural work had to take precedence. For example during the training there was a funeral that lasted for three weeks and the CRs instructed that it was not respectful to undertake research activities during that time. Finally, the term ‘research’ was a challenge because it was new.

3.2.1.2. Challenges for facilitators. Discomfort was identified as a pervasive experience for the facilitators; this is acknowledged as a common phenomenon, even inevitable, in effective and successfully-implemented CBPAR as a result of shifting power dynamics (Baum, 2016; Simms, 2016). That is, facilitators placed themselves in a position of uncertainty through the act of striving for equitable power relations rather than taking the role as research leaders. In final analysis meetings, CRs commented that the facilitators’ discomfort “can be a good thing because something is being born”.

Examples of discomfort experienced by the facilitators were:

- Handling tensions between cross-cultural and cross-institutional processes.
- Relinquishing of control whilst CR’s took time to translate.
- Inability to participate in the intense dialogue between CRs whilst they discussed, searched for and agreed on common (sometimes approximate) terms and meanings to describe biomedical concepts between the different dialects represented within the group.
- Negotiating a shift in original aims of the study (to seek community-driven approaches to prevent RHD, focusing on household crowding and health hardware such as washing facilities) to areas the community saw as priorities (improving nutrition, recognising ‘Strep’ infections, understanding teenagers), which did not have such well-recognised biological associations with RHD. In keeping with the principles of CBPAR, these changes were supported by facilitators who then negotiated reporting this to the administering institutions.
- The original project proposal had only planned for the inclusion of four CRs, but it was clearly important to include all interested community members and through cross organisational partnership this was possible, despite the burden on administrative staff and funding requirements.
- The realisation that a more accessible starting point for practical research experience would have been surveys or other numerical (especially population-focused) data collection tools rather than focus groups.
- The Cert ll training included the concept of participant consent as defined by institutional ethics committees. This caused discomfort for facilitators when Yolŋu research participants suggested that the consenting questions implied a lack of agency and therefore appeared patronising (Hawkes, Pollock, Judd, Phipps, & Assoulin, 2017; Morton Ninomiya & Pollock, 2017).

Finally, power shifts do not in the short-term produce changes in socioeconomic context, and facilitators were often discomforted by reminders of their white privilege in the face of the identifiable inequities in the lives of the CRs. For example, as new cases of RF and new deaths from RHD were experienced within the small community.

3.3. Outcome indicators

Here we report on findings from the data analysis using the three outcome evaluation criteria selected from the Wallerstein conceptual logic model (Wallerstein & Duran, 2010): empowerment outcomes (as demonstrated by examples of community voices being heard; critical thinking; capacities of advisory councils), changes in power relations and changes in policies and practice. As discussed above in relation to the process indicators, some evidence did not fit neatly into a single evaluation criteria, and coding required facilitators to draw on their cultural knowledge and experiences. The findings regarding OTW project outcomes discussed below demonstrate the links between knowledge ownership, empowerment and change.

3.3.1. Empowerment outcomes: community voices heard

Examples of the different ways in which community voices were heard included: the selection of the research action topics by CRs; being able and confident to explain their newly found knowledge of RHD to their family or community group (the CRs undertook a road trip to nearby communities to share learnings from OTW, we felt “good sharing our own knowledge, skills and feelings”); engaging in opportunities to participate and address regional and national Indigenous health conferences, connecting to other Yolŋu researchers, developing Yolŋu educational resources and co-authoring an article for a highly regarded online news outlet (Marika et al., 2018).

A key example of community ‘voices’ being heard was in the harnessing of traditional knowledge for ‘both-way’ reciprocal translational purposes; using locally meaningful stories and concepts as metaphors to enhance understanding of unfamiliar concepts like informed consent, or RHD pathogenesis. Facilitators came to recognise the significance of metaphors as a preferred Yolŋu way of knowledge creation (Marika-Mununggiritj & Christie, 1995). Meaningful metaphors we used include the *lipalipa* (canoe) journey as a metaphor for action research (Fig. 2),

and the *baru* (crocodile) as representing a knowledge system, where for example the eye represents critical thinking (Fig. 3). The effectiveness of metaphors as a communication tool is in the process of co-creating the required metaphor for the communication problem at hand, and for this reason we haven't listed more of the metaphors used. CRs stated that further 'balancing' of the two worlds, as has occurred in these processes, was important for future work and highly desired.

Enabling local voices to be heard was also demonstrated in the process of gaining understanding of the concepts encapsulated by the NHMRC research principles (such as reciprocity) and translating them into the local languages. This required creative thinking and deep discussions between the facilitator and the CRs, generating a 'productive turbulence' as described in the Yolŋu metaphor for knowledge co-creation of *Ganma* (also known as *Garma*) where salt and freshwater mix (Corn, 2014; Kemmis et al., 2013). Sections from the Cert II facilitator journal state

> "The second session went for more than three hours and we were joined by three new people (because they were interested), and one trainee [named] was also sent to consult with the community leader. We worked through lots of difficult conceptual thinking … defining the questions was as difficult as anything, had good community involvement and took lots of time" (24/10/17)… Similarly, in another session, "a lot of time spent on 'respect' – defining it both in English and local languages" (26/10/2017).

Finally, the 'Throat Swabbing Day' was a key training opportunity to put into action knowledge about RHD causation and research processes. However, some CRs, while being trained in taking throat swabs, were confident to say that it did not feel appropriate to carry out tests on each other, and directed this activity to the local health service nurse.

3.3.2. Empowerment outcomes: critical thinking

Critical thinking, the ability to deeply question, analyse, reflect and problem solve, is described here in terms of two areas: research; and RHD (and health more broadly). In relation to training in research concepts, some CRs demonstrated a natural aptitude for grasping the abstract concepts of research, and enjoyed deep discussions, whereas other younger CRs were interested in gaining practical skills, such as using computers (as reflected in Table 2, Most Important Learnings). Critical thinking related to research was evident when discussing how combining quantitative and qualitative data can reveal deeper information and is considered best research practice. This prompted a CR to equate this 'balance' to the complementarity of the two moieties (halves) that underpin the Yolŋu language, clan groupings, culture and beliefs. Similarly the turtle was identified as a metaphor for mixed methods; turtle eggs are customarily placed into groups of five and distributed equally according to the number of people present while the turtle body holds many names and stories. Similarly, after gaining an understanding of the term research, one CR stated during final analysis meetings, "We didn't realise that our ancestors have been practicing research and passing it on" reflecting that their elders had practices of observing, interpreting and analysing that were similar to western research processes (see Fig. 2 for a metaphor that captures this similarity) (Lloyd et al., 2016; Rudder, 1993). In another example, a CR demonstrated understanding and appreciation of research skills (critical thinking) as a tool for life, commenting that: "What I got out of it personally was learning about the Problem-Plan-Do-Review cycle and using it in other areas of my life". Finally, some CRs joined the research group out of a desire to develop the critical skills they saw as important for their community leadership roles "Looking through our own thoughts about how to run the project gives us more understanding about how to run projects in the future".

Critical thinking related to RHD and health was evident during the initial one-day workshop where the RHD story was discussed from initial streptococcal infection to heart surgery. Arising from this, the group identified their three action areas for OTW: Improved nutrition; Watching out for 'Strep' infection; Understanding teenagers. From the start, CRs expressed their desire to know more and to find actions to prevent, RHD: "We don't want our kids to have heart surgery"; "We want to keep the kids healthy, community healthy, look after our land".

When CRs were introduced to the politically much-used phrase, 'Closing the Gap' in reference to inequity in Aboriginal health outcomes (Commonwealth of Australia, 2018) they commented that although the 'gap' was not their fault they hoped to be invited to work collaboratively with others to fix the 'gap'. Similarly, hearing that RHD is now almost only an Aboriginal disease caused much discussion about the reasons for this difference (Did non-Aboriginal people bring it? How did they stop getting it? What is the role of the introduced foods such as white flour, white sugar and tobacco?). The questions raised demonstrated the critical awareness-raising (conscientisation) potential of CBPAR. Through these critical thinking activities all participants were able to discuss, learn and take ownership regarding "the role of broad social/contextual/environmental factors in shaping local experiences" (Munns et al., 2017: 560).

Germ theory and details about the RHD causative bacterium were frequently emphasised as new areas of knowledge. A CR commented: "It is a new thing that Yolŋu are learning to know about germs" while another said: "We would like scientists to come and tell us about the different types of germs – the names of different germs". Applying critical thinking, one CR noted that: "People would like to know what effect germs have in people's bodies - this is like knowing that different bait live in different places and are used to catch different fish e.g. small bait at [*a nearby homeland*] catches catfish". Others stated: "It will give Yolŋu knowledge to see and understand how the germs live in people's bodies"; and crucially, making the link with risk in children: "Understanding gives a picture for the community about looking after children".

From the 'Throat Swabbing Day' report, CRs described how other community members now asked them many questions about where Strep came from and how the germs got into the body. "We learnt that people didn't realise the germs are just there, they thought they came from a long way, but they are living here". Recognising the overarching importance of primordial prevention, one CR's observation from analysing the 'Most Important Learnings' matrix data was: "If we get rid of Strep infections we don't need to worry (about understanding) RHD".

When a case of RF was diagnosed in a child in the community during the project, the anguished community response included a dissection of how this had happened despite their new knowledge of the disease. A 'root-cause analysis' approach to thinking through how to increase the chance of prevention in the future would have been unlikely prior to the project due to lack of knowledge of causal factors.

A further example of empowerment through critical thinking was the issue of how health messages are presented to Aboriginal groups by clinicians and how these messages are received. In final analysis meetings, deep discussions on this topic arose. Facilitators were aware of Aboriginal people being weary of 'negative' health messages, and of the need to apply a strengths-based approach to disrupt the normalised deficit discourse. But a new sense of the depth and angst of such statements began to be felt by the facilitators as they heard how the continual emphasis in health messages about the illnesses suffered by Aboriginal people in effect only served to generate bad feelings. A CR stated that "(Good) feelings must come first" meaning that relationships and empathy must be present before it is appropriate to deliver health messages. Otherwise the messages make people 'feel bad' and even mistrust the messenger's intentions, "Do they want to make us sick?". This discussion culminated in the CRs making strong statements such as "We have our own ways of understanding illness and health. Only by using our own words, metaphors that are meaningful to us, and a communication style that is respectful, can we hear the messaging from health professionals. This means the health messages need to be made with us rather than for us" (Marika et al., 2018).

3.3.3. Empowerment outcomes: capacities of advisory councils

This category did not generally apply in OTW as it depicts a more downstream activity and different area of research. However, two of the CRs commented how critical thinking was applicable to developing leadership and awareness in their community, such as in relation to upcoming changes in governance structures.

3.3.4. Changes in power relations

The empowering effect of health knowledge was evident in the confidence to use and disseminate new knowledge, as one CR stated: "I feel very strong now about taking care of *djamarkuli* (children)". During discussions about the mortality gap that exists between Aboriginal and non-Aboriginal people, a CR posed the question: "What are *we* going to do about it?" demonstrating a position of empowerment to take action resulting from knowledge ownership. Similarly, one CR, regarding their involvement in the Cert II training stated, "I'm doing it for my family, for my community". Another CR wanted to: "Start from our community and work our way outside to help other Homeland communities… Because RHD is new for us (all), we have to understand how to stop it". A further example of agency resulting from knowledge ownership occurred when a group of children were shown a video about RHD in Yolngu Matha and the teenagers took charge of ensuring the younger children understood the prevention messages. We believe this is an area for further exploration in the future given that teenagers (mostly girls) are often seen caring for younger children and babies. Previously, the onus to share RHD knowledge was solely vested with the health service.

The CRs with opportunities to attend or present in regional and national forums became increasingly confident in public speaking and being with other 'high level' researchers. Similarly, the final group of CRs had confidence to state when referring to health messaging, that "we need information, but given in a way that makes us feel good and the choice is ours to make". CRs are also now taking on their own actions such as creating two booklets for new parents about skin care for babies, taking an appropriate positive cultural stance (celebrating beautiful children) to aid in the recognition and prevention of streptococcal skin infections. The CRs have also taken on strategic planning to develop future research projects controlled by the community; participating in co-authoring an article for mainstream media; and requesting a page on the local Aboriginal Corporation website (strategically promoting OTW prior to requesting funding for new research).

Empowerment arising from knowledge ownership was also demonstrated in the passage of power from the academics involved in devising the original study plan to the CRs as the CRs determined that their priorities were not about focusing on individual behaviour change but instead, focusing on whole-of-community priorities - improved nutrition, watching out for 'Strep' infection and 'understanding (all) teenagers'.

These actions contrast with responses to more conventional examples of health-promotion campaigns to improve RHD awareness from other communities experiencing RHD that were found to be "commonly based on deficit cultural constructions that produced internalised racism, conflict and stress for participants. Knowledge about the secondary prevention methods for RF was found to be limited" (Anderson et al., 2015: 67). That is, when "health messages are made with us rather than for us" (Marika et al., 2018) there is greater potential for empowerment.

3.3.5. Changes in policies and practices

Changes in local practices relating to health were observed such as a CR taking a child to the clinic for treatment of skin sores who might otherwise not have sought healthcare. The quote above ("I feel very strong now about taking care of *djamarkuli* (children)") illustrates the intention and capacity to do things differently, a shift to a sense of agency in healthcare practices. CRs' initiatives such as the Healthy Skin books will further sustain local practice changes.

Changes in national-level policy are underway as a result of the knowledge exchange processes undertaken. Findings from OTW have been shared with RHD Australia, the national organisation supporting RHD policy development and dissemination, and have contributed to the prominence of recognition of culture in how RHD care is delivered (RHDAustralia, 2018). Concepts on culturally-appropriate respect in messaging in health literacy derived from OTW will appear in the upcoming third edition of the national guidelines (RHDAustralia (ARF/RHD writing group) (2012)). Inclusion of OTW CRs in academic forums (e.g. meetings of the national END RHD Centre of Research Excellence) has provided a mechanism to ensure that Indigenous voices stay front and centre in research on RHD (End Rheumatic Heart Disease Centre of Research Excellence https://endrhd.telethonkids.org.au/news–events/2018/june/on-track-watch-community-researchers-visit/.org.au/).

4. Discussion

Empowerment is a chief requirement in enabling communities to find locally appropriate solutions to preventing health conditions associated with social and economic disparity. This evaluation of a CBPAR project provides guidance about factors that support engagement and effective partnerships in relation to RHD and health research concepts. Specifically, the study highlighted the need for community voices to be heard (including in setting the research agenda); for critical thinking to be fostered, and for shifts in power relations to be expected as a result of the process undertaken. As well as providing guidance about putting principles into practice, this theory-based evaluation contributes to a more nuanced understanding of ethical and empowering research principles.

While previous studies have struggled to partner with local groups using a clinic-centred approach (Read et al., 2018), the OTW both-way learning processes harnessed an enthusiasm for learning about research, and supported the locally-driven commitment to eliminating RHD. It therefore achieved a high level of community participation. Previous work has described the frustrations of healthcare providers who feel that their Aboriginal patients wilfully choose to ignore health information and medical advice (Read et al., 2018). However, OTW, alongside other qualitative work on the 'lived experience' of RHD (Mitchell, Belton, Johnston, Gondarra, & Ralph, 2018), conversely shows the profound lack of knowledge within Aboriginal communities, resulting from processes that have constrained access to and ownership of information. This lack of knowledge is evident at broad levels (knowledge of 'closing the gap', a national campaign) and at the family level (RHD literacy among families who are directly impacted by the condition). Meaningful both-way co-creation of knowledge in this setting required all six NHMRC Principles, especially reciprocity. This is almost always missing from mainstream efforts to convey information, be it in the media, the medical clinic or other forums. This highlights the critical nature of both-way learning processes if knowledge exchange strategies are to be empowering (Cairney et al., 2017; McPhail-Bell et al., 2018) and the value of the social sciences in providing alternatives to clinical and biomedical approaches (Spray, 2018).

In OTW, reciprocity was identified as a key to empowerment and was enacted by the external research facilitators through a reciprocal co-design process (Pratt, 2018) which sought to value traditional knowledge and methods throughout, and to respond to the questions, ideas and requests of the CRs. OTW demonstrated that a strengths-based approach based in both-ways practices that emphasise "working together respectfully, cooperatively and flexibly, recognising strengths and differences and acknowledging the different and the particular histories and contexts of Indigenous communities" (Arnott, Guenther, & Williams, 2009:66 cited in Guenther, Gurruwiwi, & Donohoe, 2010) serves to contradict commonly-held patronising views of Indigenous peoples and their communities as a set of problems, or as having deficits which need to be overcome (Kemmis et al., 2013).

The practice change outcomes and the thoughts articulated by CRs, especially around the desire to further disseminate learnings, testifies to

the empowering nature of co-creating knowledge, and supports the theory that decolonising research approaches which value Aboriginal knowledge (Dudgeon et al., 2010; Wain et al., 2016) can change power dynamics. Indigenous researchers in other domains, for example Fredericks et al. (2015) and Ober (2017), have documented the use of metaphors as a familiar sense-making mechanism, noting that an understanding of context is an essential aspect of understanding metaphors. Metaphors provide a collaborative and creative way of knowledge creation where knowledge holders push the boundaries to incorporate both-ways teaching and learning in a real way, allowing everyone to contribute (Ober, 2007). The key here is a sense of Aboriginal ownership of co-created knowledge that shifts the health education discourse, such that there is no longer a singular 'right' knowledge to be imparted to those perceived as 'in need' of being informed. Co-creating involves critical thinking, and is the means to "a conscientising—and therefore liberating—education" therefore "it is not that transfer of neatly wrapped knowledge; it is the true act of knowing" (Freire, 1974:27). This message is of critical importance for health and education agencies who are tasked with the development of health literacy messaging about RHD and other Aboriginal health priorities. Creation of educational resources must incorporate participatory practices, to avoid the trap of investing in the development of resources that do not get utilised, and do not generate community understanding. Similarly, we suggest the discourse of self-management needs critical examination in future work as it potentially co-opts the language of 'empowerment' in the service of ensuring patient compliance (Powers, 2003). 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 given that teenagers are often the carers of younger children and babies.

The principle that good CBPAR allows a community to define the issues to be included in the research (Pratt, 2018) has often been overlooked by external researchers who come to a project with a predetermined idea of a problem (Baum, 2016). In this context community control in determining the research priorities/agenda is an effective and accessible indicator of critical thinking (and in turn empowerment); recent publications regarding evaluation of Indigenous research concur (Pratt, 2018; Tsey et al., 2016). Further, by redefining ownership of knowledge, research priorities are unlikely to be as expected by the non-Aboriginal/external academics (Pratt, Merritt, & Hyder, 2016). This was experienced in OTW where the emphasis in the initial project proposal on individual 'behaviour change' was relinquished, and in its place there was acceptance of Indigenous collectivist framing of the research problem and areas for action: improving children's nutrition, recognising 'Strep' infections and understanding teenagers (not just supporting those on regular injections). In each of these areas the CRs sought to provide an uplifting, positive and strengths-based, community level approach through actions such as cooking and sharing a community midday meal and resources such as the healthy skin books.

All three areas of the community-defined research agenda represented a shift from an individualistic to a collectivist whole of community approach. This finding also supports our suggestion the discourse of self-management needs critical examination and the health care focus should instead be on support group or community care. These shifts in discourse represent power shifts that often appear subtle. This is to be expected, they are the micro resistances described by Foucault (Foucault, 1991) that are significant in a context where a lack of power to act can constrain the voice of CRs. This can take place in seemingly small ways, such as being shy to speak; finding the language used confusing; being unused to having a forum to negotiate priorities (therefore unfamiliar and unskilled in negotiating); and CRs not understanding the academic researchers' agenda or interests (Pratt, 2018: supplemental file 2).

The above factors reflect a Foucauldian conceptualisation of the 'power/knowledge' nexus where power is established and actioned through accepted forms of knowledge, scientific understanding and 'truth'. Empowerment (a shift in power) can only occur through critical engagement with the discourse 'of those who are charged with saying what counts as true' (Foucault, 1977:13). As knowledge ownership shifts so do power relations, in turn opening the field of possible actions. This is similar to the shift in discourse from knowledge translation to knowledge exchange (Greenhalgh & Wieringa, 2011). Conversely, having a sense of knowledge ownership diminishes the sense of being disempowered (also spoken about during OTW as alleviating the stress of having confusing information).

As should be expected, these shifts in focus, along with other examples, put pressure on the project facilitators as the project no longer aligned completely with the original, funded proposal. Deviating from expected pathways increased the possibility of tension between the facilitators and institutional processes. However, we argue that any discomfort is worth the possible longer-term outcomes of proceeding in an empowering manner and may lead to a reduction in RHD as a result of increased ownership by the community.

We believe projects such as OTW have the capacity to achieve decolonising outcomes (Smith, 1999; Nakata et al., 2012) by enhancing the capacity of participants and their communities to take greater charge of issues affecting their health and wellbeing. In particular, building CRs' "sense of self-worth, resilience, problem-solving ability, ability to address immediate family difficulties as well as belief in the mutability of the social environment" (Tsey et al., 2007: S34). Additionally, empowerment theory suggests that increased wellbeing comes from recognising and promoting the value of Indigenous knowledge (Dudgeon et al., 2017; Laliberté et al., 2009), experience and views as a "means of re-asserting control over country, livelihoods, and knowledge impacted through colonization" (McPhail-Bell et al., 2018:3). This lends support to the assertion that CBPAR projects such as OTW have the capacity to be part of the journey in healing from the effects of colonisation.

Finally, tensions such as those reported here between institutions and CRs indicate that it is not enough to simply use the rhetoric of CBPAR; there are important learnings to be had from examining the challenges of putting principles into action. Despite only limited examples where other researchers have done so, using the decolonising NHMRC principles as framework to evaluate project processes allows us to provide feedback on the principles based on practical experience. That is, the challenges in applying the NHMRC principles in practice (Markiewicz, 2012) required critical thinking that was ultimately creative and informative (productive turbulence). For example, as defined by the NHMRC guidelines, the principle of 'responsibility' did not reflect the Yolŋu lived experience where responsibility is so integrated into daily life there is not a specific term for it[3] . This suggests that although the guidelines have been developed with input from Aboriginal people, the principles tend to be defined from an institutional perspective rather than a perspective where a local community instigates research or has agency and control in their own lives and communities. Further, despite the underlying decolonising and empowering theoretical stance, the NHMRC guidelines fail to advocate for some of the key principles recognised as essential in Indigenous research, including the linkages between research, community development and social change (Dudgeon et al., 2010). The Human Research Ethics Committee (HREC) system and values and ethics guidelines are valuable tools, however limitations in the principles combined with a tendency for HRECs to rigidly pursue adherence rather than seeking to apply the spirit of 'guidelines' can become another colonising practice

[3] By way of contrast, the Lowitja evaluation report refers to *shared* responsibility and defines this in terms of the central involvement of Aboriginal people and communities (including strength of partnership, attention to power sharing and the right to self-determination) and includes the related principles of accountability (Kelaher et al., 2018).

(Hawkes et al., 2017).

4.1. Evaluative research learnings

In a complex context, evaluation is more than a mere "technical" problem (Tsey et al., 2016), rather, a culturally appropriate, reflexive, context-specific evaluation is required. Outcomes from the evaluation of the type of CBPAR project we have conducted should not necessarily be predictable, if good processes are followed (Cairney et al., 2017; Dudgeon et al., 2017; Laliberté et al., 2009; McPhail-Bell, Bond, Brough, & Fredericks, 2015). The focus on collaborative knowledge generation using participatory learning-by-doing approaches based on principles of trust, respect, reciprocity, equality and responsibility, inevitably leads to outcomes not anticipated at the study's outset. This means that logic models have a place but they can be constraining if taken too rigidly (Greenhalgh, Jackson, Shaw, & Janamian, 2016). Additionally, as expected in a short-term project, outcomes will be embryonic but indicative of future growth. A project that followed similar CBPAR processes to those described here considered ten years as an appropriate time frame to commence evaluation of their work (Onnis, Klieve, & Tsey, 2018).

Therefore, we suggest that evaluations in this context need to focus on process indicators that value "relationship building and the research process, rather than the usual emphasis solely on outcomes" (Dudgeon et al., 2010: 84; Hughes, Docto, Peters, Lamb, & Brindis, 2013). Including community perspectives regarding a project's research processes is important as it will only be after research has been conducted that researchers prove themselves trustworthy (Dudgeon et al., 2010). Similarly indicators are needed that reflect the realities of rebalancing relations of power within the research process, not just the theory as happens in many research proposals (Gwynn et al., 2015). Process evaluations can identify the factors that limit empowerment such as orthodox structures of research funding and governance (Salway, Chowbey, Such, & Ferguson, 2015:12). For example, critical thinking on the part of CRs can be difficult to identify, as normative interpretations, fear, and lack of external perspective, impact on the time taken to articulate or see problems differently (Salway et al., 2015). Thus, as suggested by Wallerstein and Duran (2008:387), 'measurement efforts should focus on the ability of interventions to reach culturally and deeply into the communities served'.

Finally, in addition to a focus on theory-based process indicators, research methods need to be adaptable to local conceptualisations about research. Mixed methods approaches ensure the inclusion of a broad scope of information, allowing for triangulation particularly when process indicators are linked to an appropriate theory of change, such as the emancipatory potential of CBPAR. This methodological rigour contributes to the generalisability and transferability of evaluation results (Chen, 2012; Dudgeon et al., 2010; Hughes et al., 2013). In OTW, as expected, both-way learning processes contributed not just to RHD knowledge acquisition, but also to a better understanding of appropriate methods of data collection (Cairney et al., 2017; Dudgeon et al., 2010; McPhail-Bell et al., 2015; Tsey et al., 2016). For example, it became clear that asking questions is not the preferred way of gaining knowledge. Rather the Yolŋu traditionally seek knowledge through '*nhina ga ŋäma ga nhäma*' [literally "sit, listen and observe"]. This is a cultural educational stance of observing a practice (how a task is done), and listening (to spoken instructions or for instance to a dance beat) and joining in as a process for learning that is distinctly different to asking questions. The CRs identified this as a research method once it was recognised that the western term 'research' was akin to the kind of listening, observing, analysing and reflecting that "our ancestors have been practicing".

Similarly, the usefulness of metaphors as a culturally appropriate 'all teach all learn' process for generating both-way learning became clear (McPhail-Bell et al., 2018). The metaphors reported here are context-specific and it should not be assumed that they can be applied elsewhere. That is, the specific metaphor is not directly transferable to another context, while the process is.

4.2. Limitations

While findings from this study are theoretically generalisable, a possible limitation is the extent to which recommendations can be replicated in other CBPAR projects. That is, there were a number of unique, context-specific factors. There was limited previous experience of medical research in the community involved in this study, so there was not the sense of being over-researched as is articulated elsewhere. The previous experience of research (an anthropological study) had delivered positive outcomes for the community in the form of a widely celebrated sea rights determination (Barber, 2013). As a result of this and a relationship built over many years by A.G.M. the project had formal approval from community leaders. Also the principal researcher's ability to live in the homeland for an extended period (coinciding with data collection for doctoral research, a separate project) made it easy to participate in local community and cultural events, including important ceremonies as well as daily activities such as hunting, child care, community sports and Christian fellowship. Accepting and living according to roles as determined by adoption into a family/clan group (such as mother, sister, grandmother, daughter) meant inclusion as part of a collective, no longer having an individualistic identity. This was commented on by both community leaders and members of the OTW group as evidence of a commitment to both-way learning. And without the flexibility to extend the Cert II training over a two-year period we would not have had so many CRs graduate or time for the lengthy both-way learning processes.

Finally, we were not able to measure health impacts according to numbers of streptococcal infections, RF cases or new RHD diagnoses. Such outcomes, especially the latter, would need to be measured over longer time periods.

5. Conclusion

The OTW project was a pivotal opportunity for institutional researchers to be invited into an Aboriginal community to co-create a foundation for RHD elimination. The evaluation reported here provides practical guidance in implementing empowering and decolonising principles/theories. CRs engaged in the project expressed a deep desire to know more about RHD in culturally meaningful ways. CBPAR provided an appropriate methodology where both-way learning led to empowerment and a sense of urgency in communicating and sharing the RHD story widely across the community. Principles learned during OTW are highly valuable in the next stages of the RHD elimination strategy which will include scale-up of community engagement and empowerment through knowledge ownership. The OTW project also achieved sustained local community appreciation of the benefits of research that promotes Indigenous knowledge, experience, perspectives, control and strengths-based approaches. The Cert II qualified CRs will be sought after as content experts in future research and RHD advocacy activities or as members of Indigenous research advisory panels. The success of this approach to preventing RHD can have broad-reaching benefits in reducing adverse outcomes of childhood infection and informing other projects aiming to address health inequity, provided there is systems-level and infrastructure supports in place. As identified by this evaluation, we advocate for a focus on emancipatory process indicators in project implementation and evaluation. This has implications for funding and ethics approval processes as well as evaluation criteria and methods. Finally, we need to ensure the learnings from CBPAR projects such as OTW are absorbed and implemented by 'mainstream' western biomedical researchers, particularly the value of including community researchers, and involving community in determining the research agenda.

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