


Tuberculosis care designed with barramarrany (family): Participatory action research that prioritised partnership, healthy housing and nutrition

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Funding information

Sue Devlin's Doctoral studies are supported through an Australian Government Research Training Program Scholarship.

Handling editor: Kalinda Griffiths

Abstract

Issue addressed.

Ongoing tuberculosis (TB) transmission in Aboriginal communities in Australia is unfair and unacceptable. Redressing the inequity in TB affecting Aboriginal peoples is a priority in Australia's Strategic Plan for Tuberculosis Control. Improving TB care needs not to just identify barriers but do something about them. Privileging the voices of Aboriginal people affected by TB is essential to identify effective and enabling strategies.

Methods: A barramarrany (Aboriginal family) affected by recurring TB partnered with TB and Environmental Health teams using a participatory action research (PAR) methodology to improve housing health hardware and nutrition alongside biomedical TB prevention and care. A combination of the Ottawa Charter for Health Promotion; the International "End TB" Strategy; and Aboriginal barramarrany leadership, world-views and traditional values guided actions to reduce TB transmission.

Results: Together the partners improved housing hardware and access to nutritious food, so the barramarrany could create a setting for good health and wellbeing. These actions supported the barramarrany to regain the physical, social and emotional wellbeing to deal with day-to-day challenges and stresses. The barramarrany were able to better sustain supportive relationships; grow, prepare and eat healthy food; and participate in health care activities. The barramarrany could better engage with medical approaches for TB and four barramarrany members completed TB treatment. The PAR action-project enabled and supported early TB diagnosis, treatment and prevention.

Conclusion: Amplifying the voices of Aboriginal people and shared ownership of TB diagnosis, treatment and prevention by the barramarrany, was underpinned with principles of self-determination, capacity building and social justice. This PAR

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action-project provides further evidence that improving housing and nutrition can assist in Ending TB while improving wellbeing.

So what?: Our action-research project undertaken within a PAR framework demonstrates the implementation of End TB Strategies by utilising the Ottawa Charter's five actions to promote health, by understanding and centralising the social determinants of health.

KEYWORDS

aboriginal and torres strait islanders, environmental health, health promotion, nutrition, participatory action research, partnership, social determinants of health, tuberculosis

1 | INTRODUCTION

In the ongoing challenge of Tuberculosis (TB) control countries are encouraged by the World Health Organisation (WHO) to know their epidemic and to adapt the WHO End TB Strategy to “on the ground” situations.¹ The TB incidence in Australia is a low and the majority of people diagnosed with TB were born outside of Australia in countries with a high TB incidence.² Of the people diagnosed with TB who were born in Australia, Aboriginal and Torres Strait Islander people are disproportionately represented. The annual notification rate for Aboriginal and Torres Strait Islander people (4.8/100 000 people in 2015) is 6 times the rate for the non-Indigenous Australian-born population (0.8 per 100 000 people).² Redressing the inequity in TB affecting Aboriginal and Torres Strait Islander people through “identifying barriers to improved tuberculosis care” has been priority action in *Australia's Strategic Plan for Tuberculosis Control – towards elimination* but rates remain high.² Improving TB care needs not to just identify barriers but doing something about them.

This research was undertaken in the state of New South Wales (NSW), Australia, on unceded Aboriginal land. In recognition that Aboriginal people are the original inhabitants of NSW, the term “Aboriginal” is used in this paper. The term Aboriginal people/s in this paper refers to the individuals, families and communities directly involved in this research, with the term Aboriginal and Torres Strait Islander peoples used when discussing all of the First Nations people in Australia. These terms were determined by the Aboriginal researchers and endorsed by all other researchers in the project team.

To really improve TB care would require health services being aware of, and reconfiguring, power relations in favour of Aboriginal and Torres Strait Islander people.³ Improved TB care requires Aboriginal and Torres Strait Islander people to have a real say in the development of TB policy and programs that represent the realities of life and desires of Aboriginal and Torres Strait Islander peoples.^{3,4} The outcome of this would be Aboriginal and Torres Strait Islander people having shared ownership of TB prevention and care decisions with the ultimate goal to “End TB” in all parts of the Australian community.

A systematic and integrative review of literature published between 1879 and 2018 reported that the historic and contemporary

burden of TB is underpinned by Aboriginal and Torres Strait Islander peoples' dispossession, disempowerment and cultural disintegration by European invasion of the lands now called Australia.³ Despite TB inherently being a social disease, TB care in Australia predominantly has a one-size-fits-all biomedical approach.³ The voices of Aboriginal and Torres Strait Islander people with lived TB experience are scarce in the published literature on TB and are completely absent in publications on the development of TB policies and programs.³ How TB care actions are, or can be, led by Aboriginal and Torres Strait Islander people, and how the inclusion of Aboriginal and Torres Strait Islander people in decision-making processes can be a TB care strategy, are not present in the TB literature. This paper aims to address some of this.

Aboriginal people in northern NSW with lived experience of TB have highlighted that family must be central to TB care, and that TB care must promote the strong family ties that are a feature of Aboriginal and Torres Strait Islander peoples' cultures. The Aboriginal people engaged with TB services in northern NSW have regularly reinforced that TB is linked to the living conditions conducive to health—this is the social determinants of health. Because the social determinants of health are the circumstances in which people are born, grow, live, work and grow old as well as social justice issues such as inequities in power and resources, it is essential to incorporate these in TB prevention and care.⁵⁻⁷

The relationships between social determinants of health and TB are complex and involve links between factors that influence health and wellbeing on several levels. The social determinants of health approach emphasises “upstream” or population level factors based on how social and economic systems are organised.⁸ The factors include level of income, food security, housing and working conditions.⁹ Upstream determinants influence “downstream” factors that include the specific conditions or behaviours of people to the conditions of poor health and subsequent manifestation of disease. Importantly, social determinants of health models also include protective factors such as social networks and social cohesion.¹⁰ There has been strong advocacy to expand the lens of TB control efforts globally to address the social determinants of the disease and not just the disease itself.^{5,11-14} The World Health Organisation Sustainable Development Goals¹⁵ and the End Tuberculosis

Strategy,¹⁶ for example, advocate for health promotion actions focused on social determinants of TB.

Housing and nutrition are well recognised as key social determinants of health influencing the risk of infection with TB and the course of TB disease.^{5,11-15,17-20} Globally, there is evidence that Indigenous communities often have a high prevalence of factors that exacerbate risk for TB such as diabetes, alcohol and tobacco consumption.⁶ However, there is little evidence supporting specific approaches to address social determinants of health for TB prevention with Indigenous people.⁶

Despite 20 years of responding to a TB outbreak affecting some Aboriginal families in northern NSW,²¹ there had been no specific approaches documented for community-led, culturally appropriate strategies that directly engage in the social determinants of TB with the affected Aboriginal families and communities. The TB outbreak comprises more than 50 Aboriginal people diagnosed from 2000 to 2020 with drug-sensitive TB. Half of all TB diagnosed in Aboriginal and Torres Strait Islander peoples in NSW between 2003 and 2015 were from people who lived in the northern NSW region but only 9.4% of the Aboriginal and Torres Strait Islander population live there.²¹ TB transmission continued in northern NSW despite the rigorous implementation of the standard biomedical TB control strategies of enhanced TB screening programs and people with active TB disease completing treatment.

In response to the ongoing risk of TB, a community-based TB Participatory Action Research (PAR) program is ongoing in northern NSW to build new and shared knowledge between Aboriginal people and health care personnel, managers and policy makers on the realities of TB prevention and care with Aboriginal peoples. The TB PAR aims to amplify the voices of Aboriginal people affected by TB, and to identify effective and inclusive TB care strategies with (not “on” or “to” or “for”) Aboriginal people in this specific context.

Here we present an action-project within this TB PAR that centralises a family-led social determinants of health approach into TB care with an Aboriginal Gumbaynggirr barramarrany.¹ The project's primary objective was to stop TB transmission within a large Aboriginal barramarrany, comprising a father and his 14 children living in an owner-occupied house in a suburban street in a rural town.

The context of the PAR action-project was integral to the shared approach and shared outcomes. As a result of TB remaining within the barramarrany the family members were faced with the prospect of TB screening or treatment for the fourth time in a ten-year period following close contact with a person with TB. The barramarrany voiced to trusted long-term health care providers in the TB Team, that the barramarrany were overwhelmed, fatigued and stressed by ongoing TB screening and treatment (past and present) that compounded other health and social issues. The barramarrany voiced frustration that TB had not stopped even though there was good adherence to previous TB screening and treatment by all barramarrany members. Because of the trust that had been built over time between the barramarrany and TB Team, deeper discussions exploring the challenges of everyday life ensued (see Box 1). This dialogue led to more of a shared understanding between the barramarrany

BOX 1 Example of how dialogue was fulfilled during the PAR action-project

The father of the barramarrany, an Aboriginal health worker and two non-Aboriginal nurses from the TB Team sat together in the front yard at the barramarrany house. Father drew circles with a stick on the ground to emphasise the exhausting cycle caused by TB that his barramarrany were experiencing. He presented his vegetable garden and a bush tucker tree as testimony. He described the garden as previously being a nurturing place for his family, as well as a source of healthy food. The vegetable garden was barren and disused, and the bush tucker tree was wilting. The father explained that for years TB had stolen energy, strength and time he needed to protect and nurture his children and to tend the garden.

and the health personnel that the families' physical house condition and food security were undermining good health and wellbeing for the barramarrany. It became obvious that despite the barramarrany remarkable strengths and resilience, the previous episodes of TB within the barramarrany had taken a severe toll on the ability of the 15 people in the house to function on a day-to-day level. This accelerated the barramarrany existing/ongoing housing functionality and wellbeing challenges. The father of the barramarrany disclosed he did not know where to start to repair and improve the living conditions for his 14 children and he entrusted the TB Team to explore options to redirect the barramarrany wellbeing trajectory.

The barramarrany partnered with the TB and Environmental Health teams from the NSW North Coast Public Health Unit (NCPHU) (hereafter referred to as the project-team) with a focus on (i) improving the hardware in and around the house (referred to hereafter as “housing health hardware”) and (ii) nutrition, to provide a foundation for good health and wellbeing, including the successful treatment of TB. The term “housing health hardware” is used to describe infrastructure components collectively that are necessary for healthy living practices such as washing people, washing clothes and bedding, and food preparation. Housing health hardware components include safe electrical systems, toilets, showers, taps, kitchen cupboards and benches, and stoves.²²⁻²⁶

The project-team aimed to successfully treat people with TB and prevent further TB transmission by supporting the barramarrany to maintain strong connections between the barramarrany members that are necessary to deal with day-to-day challenges of life. This would also enable the barramarrany to better engage with biomedical approaches for TB prevention. The approach was underpinned by the principles of collaboration between Aboriginal and non-Aboriginal partners, whereby the voices of Aboriginal and Torres Strait Islander people were centralised with a view to re-configuring the historical power imbalance in favour of Aboriginal and Torres Strait Islander people through the process. Aboriginal

peoples' worldviews, traditional values and cultural perspectives drove actions.

2 | METHODS

2.1 | Participatory action research

The PAR action-project described here was an action cycle within a larger ongoing PAR collaborative process between some northern NSW Aboriginal communities, health services and academics (hereafter referred to as the TB PAR). The TB PAR collaborative is exploring together the views and experiences of Aboriginal people with TB, and the role of self-determination by Aboriginal people in ending TB in the area. Action-oriented projects are integral to PAR bringing about positive change as part of the research process.²⁷

The basis of PAR is the plan-act-observe-reflect cycle for operational and theoretical learning. The diagram in Figure 1 conceptualises the cycles of learning that have developed collaboratively and iteratively over time for the TB PAR. The spiral is adapted from Lewin's cyclic model²⁸ and it represents "the explicit possibility of acting differently as a result of progressively learning from experiences".^{29(p315)} The TB PAR has been undertaken in real-world circumstances of Aboriginal peoples' lives, and amongst the delivery of TB services. So, the cycles were not implemented in a linear fashion as this diagram suggests but with simultaneous plan-act-observe-reflect cycles using qualitative data collection and analysis methods. The project-team's observations and reflections from this action-project were incorporated into the spiral of progressive learning to contribute to the development of new understandings to inform health system change to end ongoing TB transmission in Aboriginal communities.

PAR is known to be a research methodology preferred by Aboriginal communities because it is focused on ownership by the communities involved.²⁷ PAR is a decolonising methodology that aims to be transformative and is concerned with relocation of power to the Aboriginal communities involved.²⁷ The TB PAR is based on a participatory worldview, privileging relational practice and building partnerships.

The TB PAR applies the six core values for ethical research with Aboriginal people and communities—spirit and integrity, cultural continuity, equity, reciprocity, respect and responsibility.³⁰ The TB PAR has the approval of the Human Research Ethics Committees of the Aboriginal Health & Medical Research Council, North Coast Health Service L and James Cook University. The participating Aboriginal communities retain ownership of the TB PAR outputs.

At the barramarrany request, the Environmental Health Team undertook a functionality assessment of the barramarrany privately-owned house to identify and cost issues that affected health and safety. The Environmental Health Team applied the principles of the 9 Healthy Living Practices²⁴ gained through experience with the NSW Health's *Housing for Health*[®] program.^{22,23} The partners then sat down and identified together ranking of repairs and maintenance activities aimed at increasing the ability of the family to gain health. An agreement was established that some repairs would be undertaken by the barramarrany independently, and that others required the physical or financial support of the NCPHU.

During the planning and implementation stages of the PAR action-project the TB team identified a range of affordable and accessible healthy food options with the barramarrany that were supplied in a weekly food hamper as a supplement to TB medication. In addition, the TB team provided advice on food preparation and practical recipes for the family of fifteen. The barramarrany then re-established a back-yard garden to grow fresh and nutritious food.

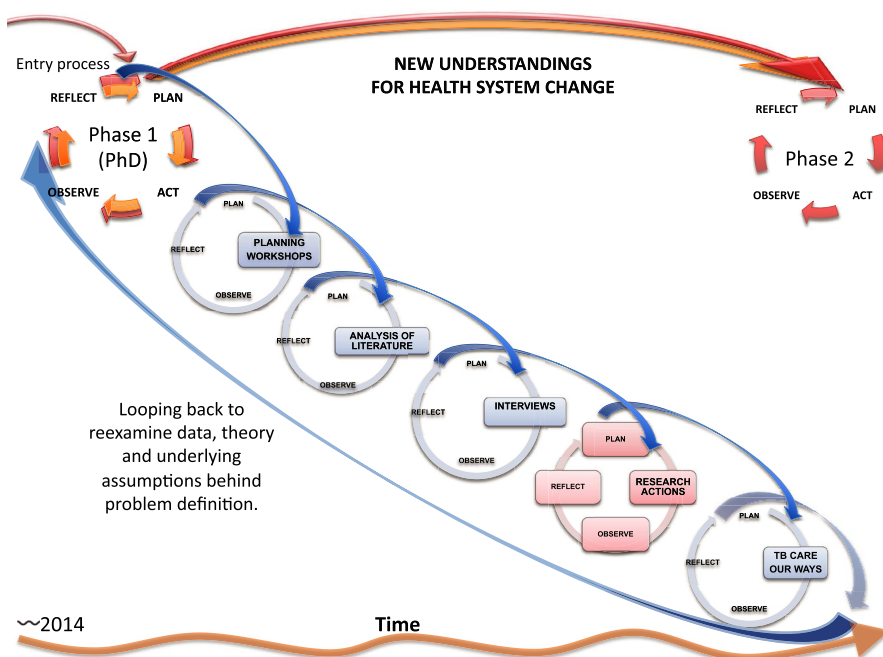


FIGURE 1 Application of Lewin's cyclic model²⁸ for the TB PAR

During the project, the father in the barramarrany asked for assistance to tackle some longstanding health issues for the children, such as getting up to date with immunisation and eradicating scabies. The TB Team supported the barramarrany with visiting the local Aboriginal Community Controlled Health Organisation (ACCHO) to tackle these issues.

The action- project was evaluated to assess the outcomes with the barramarrany in three domains (i) social; (ii) health and wellbeing; and (iii) TB disease-specific. The experiences and reflections of the father of the barramarrany were recorded during informal discussions with the TB team throughout the project and during a specific debriefing session at the conclusion of housing repairs. Several months after completion of the set of PAR actions, the father of the barramarrany participated in an in-depth interview with Aboriginal and a non-Aboriginal health workers/researchers from the TB Team. The father described his TB-related experiences and his interactions with health services and personnel. He then recommended specific approaches for TB prevention and care with Aboriginal people. The interview was recorded and transcribed verbatim and analysed by Aboriginal and non-Aboriginal researchers. Interview content and collaborative reflections specifically related to this PAR action-project are presented in the results/findings and discussion below.

The father's interview transcript was also included in the larger TB PAR dataset where transcripts were coded to identify broader themes or patterns in the experiences of Aboriginal people with TB. The themes were then explored collaboratively through the plan-act-observe-reflect PAR process to develop understandings of the associations between the topics identified and will be reported in detail elsewhere.

3 | RESULTS/FINDINGS

The analysis of the in-depth interview and reflections identified six themes:

- Action to improve housing health hardware
- Action to improve nutrition
- Improvements in health and wellbeing
- Improvements in TB screening and treatment
- Improvements in social and cultural spheres
- Sharing success and knowledge with others

Action to improve housing health hardware

The barramarrany and health services identified improving housing health hardware as essential to End TB in the barramarrany. The improvements essential to health and to end TB were identified as: re-establishing indoor bathing facilities; replacing taps in the bathroom, kitchen and laundry that enabled safe food preparation and sanitation; replacing water-damaged structures; repairing faulty electrical wiring, smoke detectors, lights and switches. The partners identified together the scope of repairs that were undertaken

by the barramarrany independently, or with the physical or financial support of the NCPHU and social support agencies. The Aboriginal Health Worker from the TB Team was present when building and trade contractors visited the house to assist the barramarrany to navigate the experience of living in the midst of home renovations. Contractors were selected that had experience with working with Aboriginal people alongside the Environmental Health Team or were known to the family. The barramarrany were provided with information and strategies to assist with ongoing maintenance of the house and to minimise and manage utility bills.

It is not usual practice for NCPHU to repair privately owned houses and so careful consideration was given to the ethics and broader impacts of the NCPHU repairing this house as a part of TB prevention and care. Factors which influenced the release of funds for repairs included: the large size and composition of the household; the magnitude of the health and social consequences if the house repairs were not done; the contribution of past TB to the barramarrany current circumstances; the inability of the house to be included in an existing program such as *Housing for Health*[®] due to private ownership. The NCPHU managers understand and support self-determination by Aboriginal people, and value the social determinants of health approach and innovation. Guidance and backing was obtained from the barramarrany extended family and from Aboriginal health personnel with extensive experience in health promotion. Leadership provided by the Aboriginal partners ensured the barramarrany worldviews, traditional values and cultural perspectives drove decisions. Throughout the project, ownership of the barramarrany health and wellbeing remained with the barramarrany.

Action to improve nutrition

The barramarrany and health services identified improved nutrition as essential to End TB in the barramarrany. A weekly healthy food hamper therefore supplemented TB treatment and a vegetable garden was established to sustain good nutrition. It is customary for the North Coast TB Team to offer enablers such as fruit and vegetables to people taking TB treatment. All partners understood the resurrection of the barramarrany vegetable garden was integral for improving and sustaining the barramarrany healthy eating.

Initially, the food hamper was offered as part of the TB treatment prescription. A weekly financial budget for food was established with the barramarrany that was identified as sustainable for the context. Prior to shopping the TB Team discussed food preferences with barramarrany members. The TB Team introduced in-season fruit and vegetables along with barramarrany favourites. The younger children were excited to discover and try what was in the hamper each week. The older barramarrany members asked for advice of how to cook the new foods. So the TB Team and barramarrany explored together ways to produce thrifty, nutritious meals for the household of fifteen people that included adults, teenagers and pre-teens. The TB Team obtained assistance from the Health Promotion Unit and free recipes were collected together from the local supermarket describing how to cook with seasonal produce.

The Aboriginal Health Worker from the TB Team assisted the non-Aboriginal partners to understand that restoration of the garden was central to the barramarrany healing. The garden provides a setting for social cohesion and shared responsibility for the barramarrany. So the vegetable garden was included in the functionality assessment as essential to sustain health and psychosocial well-being. The vegetable garden bed infrastructure was strengthened and filled with donated soil. Seed packets were included in the food hampers. The garden was flourishing at the completion of the house repairs and a sample of home-grown tomatoes were shared between the partners in celebration of what had been achieved together.

Improvements in health and wellbeing

Positive outcomes were experienced across interrelated health and wellbeing, disease specific and social domains. The barramarrany regained the ability to deal with day-to-day challenges and stresses without becoming overwhelmed.

The barramarrany expressed and demonstrated motivation to participate in health care and TB prevention activities, and family members established systems to support each other to participate. During the PAR action-project all the younger children attended the ACCHO and received catch-up immunisation and dental care. Eradication of scabies was achieved. Tuberculosis-specific outcomes included four household members completing TB treatment; all barramarrany members participating in TB screening by chest Xray; and importantly the barramarrany initiated self and collective monitoring for TB symptoms. During the in-depth interview the father of the barramarrany said,

“It ended up being a good thing because everyone helped one another with the [TB] treatment”.

In addition, healthy eating was sustained by enabling healthy food preparation; access to vegetables in the garden; and through healthy eating experiences. During the in-depth interview the father of the barramarrany said,

“Because of the veggies coming each week the family has started eating healthy, because they gained experience in how easy it is to eat healthy.”

Improvements in TB screening and treatment

The process enabled an early TB diagnosis and treatment of an additional member of the barramarrany. The early TB diagnosis was made while the disease was in the subclinical phase between latent infection and active disease. In the subclinical phase people might not have recognisable symptoms and the bacillary load is low.³¹ The improved process was not only good for the individual but also prevented other members of the household from becoming re/infected. The PAR action-project partners, including the barramarrany, interpreted the early diagnosis of pulmonary TB during the PAR action-project as a positive outcome. Early TB diagnosis meant hospitalisation was not required. The timing of the diagnosis meant the barramarrany did not have the burden of additional TB treatment, and so less interruption to school attendance, employment, family and cultural obligations. The low level of lung damage from the early TB diagnosis meant the standard short course TB treatment regimen was used and the young person has a low risk of developing TB-related chronic lung disease.

At the debriefing at the completion the father of the barramarrany stated,

“I’m glad all this was caught before it got out of hand. You never know what the outcome could have been or would have been.”

Improvements in social and cultural spheres

There was a ripple effect of positive outcomes in other social and cultural domains. These are conceptualised in Figure 2. The barramarrany established new connections with schools and social organisations; school attendance and homework increased; adults

SOCIAL DETERMINANTS OF GOOD HEALTH

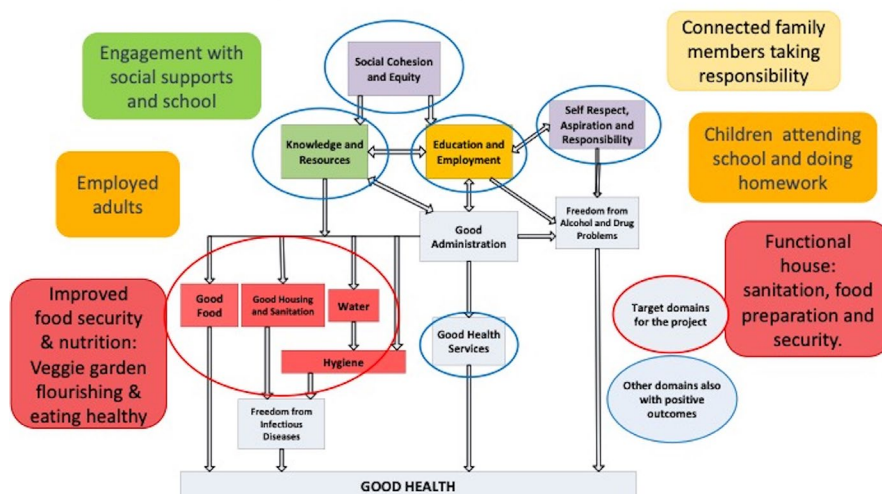


FIGURE 2 PAR action-project observed outcomes in social domains

commenced employment, training and job-seeking; and the father returned to gardening, painting, playing the didgeridoo, and providing physical, emotional and spiritual support for his children. Improved relationships between barramarrany members were described by the father in the in-depth interview and were observed by the health service partners. The treatment support model initiated by the barramarrany, and the reflections by the father of the barramarrany demonstrate outcomes in the domains of social cohesion, self-respect and responsibility. The father of the barramarrany stated:

“[The children] used to wake up angry of a morning but lately you don’t hear from them.”

At the ceremony on the completion of house repairs the PAR action-project partners exchanged meaningful gifts to celebrate what had been achieved together. This exchange embodied the reciprocity that built and maintained the relationships between the partners. The health partners presented a bush-tucker tree. The father in the barramarrany presented artworks he had undertaken during the project to the health service teams. One of the artworks is in

Figure 3. When handing over the artworks the father in the barramarrany stated,

“A dark cloud has lifted.”

At this ceremony the father in the barramarrany asked the health partners to tell other health workers:

“The small steps taken by health made a huge difference for us, and we hope others will consider these sort of approaches for managing TB.”

Sharing success and knowledge with others

The voice of the barramanny was further amplified when the father in the barramarrany contributed to a video describing the PAR action-project for the Mid North Coast Local Health District Quality and Innovation Awards ceremony. The project won the “patients as partners” category.



FIGURE 3 Artwork undertaken by the father in the barramarrany to celebrate the process and the outcome of the PAR action-project

All health partners have participated equally in disseminating the knowledge created from the PAR action-project, including authorship of this manuscript. Learnings from this project and the TB PAR have been embedded in North Coast TB and Environmental Health models of care. The presentation of the PAR action-project to managers and staff in the NSW Health TB and Environmental Health networks has opened dialogue for changes in statewide policies and programs to be more inclusive of Aboriginal peoples' local realities and the specific local contexts in which they are played out. The NSW Rheumatic Heart Disease Program is piloting an Environmental Health Response Home Assessment and Fix project that is also based on the Housing for Health[®] model and addresses specific local realities and contexts.³²

3.1 | Interpretation and discussion

The partnership formed for this PAR action-project enabled the renewal of a functioning house and improved nutrition with the barramarrany. Actively addressing these two 'determinants of health' helped end TB with this barramarrany. The collaboration and the actions undertaken by the PAR action-project partners resulted in positive outcomes in social; health and wellbeing; and TB disease-specific domains. The project-team's collective health promoting actions supported the physical, social and emotional wellbeing of the barramarrany.

This PAR action-project provides an active case-study of how Aboriginal people with TB can play a central role in the management of illness recovery. It also demonstrates how actions that are determined by Aboriginal people and supported by health services can lead to better health outcomes. This PAR action-project has demonstrated how the barramarrany was able to take a lead in TB prevention in partnership with a health service willing to adapt the End TB¹⁶ strategy to respond to the local context. Ongoing ownership of TB prevention actions by the barramarrany was made possible by operationalizing the principles of health promotion⁹ and the Global Indigenous Stop TB Action Plan into TB care with the barramarrany.⁴ The Ottawa Charter framework for health promotion action includes 1) building healthy public policy; 2) creating supportive environments; 3) strengthening community action; 4) developing personal skills; and 5) reorienting health services towards health promotion.³³ The actions are founded on the social justice values of equity, participation and self-determination.

Comprehensive utilisation of the Ottawa Charter for health promotion as the foundation for TB prevention and care is a deviation from the usual approaches that are used for TB control in Australia. TB control focuses on cutting transmission through early detection and effective treatment. TB-related health promotion is usually focused on individual behavioural approaches to improve the capacity of health services to deliver biomedical control interventions effectively.⁵ Approaches based on individual behavior change will have only a limited effect in improving health.³⁴ The systemic racism that Aboriginal and Torres Strait Islander people face to act on health

promotion messages, that are the 'usual approaches' to TB control, leaves many Aboriginal and Torres Strait Islander people behind. Improving TB care by being adaptable and having an informed and nuanced approach to preventing TB is therefore critical to uphold the human right of Aboriginal and Torres Strait Islander people to be free from TB. The "protection and promotion of human rights, ethics and equity" is one of four principles recognised by the WHO for ending the global TB epidemic.¹⁶ A human rights-based approach has been used for development of TB programs and interventions with, by and for First Nations and Metis organisations in Canada.³⁵

This PAR action-project shows that using the Ottawa Charter health promotion actions as a basis for health services to work in partnership with Aboriginal and Torres Strait Islander families can improve tuberculosis care. The human rights' foundation embodied in an Ottawa Charter approach counters the often dominant "deficit discourse" that defines Aboriginal and Torres Strait Islander people by limitations, disadvantage or deviance³⁶ through "a narrative of negativity, deficiency and failure".^{37(p2)} This project incorporated a mix of strengths-based measures and capacity building strategies (Box 2) that "enable people to increase control over, and to improve their health"⁹ through the framework for health promotion action.³³

A strength of this PAR action-project is the engagement with all five of the health promotion action areas and the interaction between action areas at structural, group and person level.³⁸ The project-team achieved the interaction between action areas by addressing material conditions that are fundamental for good health as well as attending to the socio-cultural underpinnings of the barramarrany material conditions and TB experiences.

The project-team partnership involved people with complementary but different expertise: the barramarrany, and Aboriginal and non-Aboriginal personnel from Environmental Health and TB services.³⁹ The project connected all the health promotion action areas by bringing the family/community affected by TB and multidisciplinary health teams together to listen; to talk; to make decisions; to take action; to reflect on actions and outcomes; and to advocate for senior health managers to celebrate, support, promote and resource Aboriginal-led social-focused TB care. Our project was based on the values of inclusion, self-determination and ownership by Aboriginal people.

We paid particular attention to power imbalances within the project and all associated actions. Respectful dialogue through "yarning" and use of "good talk" was central to establish and maintain the equality within the partnership. Good talk is where "clinicians give up the detached professionalism of medical voice for the yarning, social, egalitarian lifeworld voice".^{40(p144)} Talk was conceptualised as a medium of health "care" and a medium of power. "Good talk" was identified in minimising power differentials between Aboriginal community members and the health care system that is necessary for cultural safety in health care.^{40,41} Yarning is described by Aboriginal Elders as discussion and connecting and it is a form of information exchange "that embodies the oral traditions of Aboriginal peoples".^{42-44(p2)} The yarning in this project enabled people to equally share information and to co-learn. Non-Aboriginal

BOX 2 Summary of how health promotion actions were operationalised to enable the barramarrany to increase control over their physical, mental and social wellbeing

- (i) The partnership approach provided structure for strengthening community action; development of personal skills for personal and social development; and creating a supportive health care environment
- (ii) Engaging the barramarrany leadership and partnership to promote healthy living as a foundation for TB prevention
- (iii) Development of a supportive physical and social home environment to facilitate healthy choices by barramarrany members
- (iv) Establishing a physical and social setting with the barramarrany to enable good health
- (v) Development of personal skills by the barramarrany to increase control over factors for health and wellbeing
- (vi) Development of personal skills by the health partners' to augment understanding of why and how to include cultural values in the design and delivery of services
- (vii) Reorientation of health services to address social determinants of health alongside biomedical TB treatment and investigation
- (viii) Development of healthy public policy through advocacy for NSW Health to engage in collaborative development of policy and guidelines that are inclusive of Aboriginal peoples perspectives and broader incorporation of health promotion actions in health care.

people involved in the project reflected on their beliefs and behaviours through this process and were willing to surrender the power inherent, as a consequence of employment positions and/or dominant social position/paradigm, to enable the barramarrany and the Aboriginal people involved in the project to lead and own decisions throughout the project.

Existing reciprocal trusting relationships between the extended barramarrany and long-term members of the TB Team (both Aboriginal and non-Aboriginal) were essential in this project.⁴⁵ This relationship was built through prolonged engagement over a decade through family-led clinical interactions and community-based participatory research. The long-term TB Team members provided the bridge for confidence and trust to grow between the barramarrany and the other health partners. Building a family-approach to health care takes significantly more time than is required for delivery of services that are not relational. The time taken to build relationships, yarn with family members and develop shared understanding does not fit neatly into clinical intervention services.⁴⁶ But it is time for

the system to change. A family-approach can have generational effects on preventing disease and advancing health and wellbeing.⁴⁷

Building trust with new people and maintaining trust with long-term people was an active process that involved plan-act-observe-reflect cycles of dialogue to corroborate goals, values and actions each time the partners interacted. Health service partners established trustworthiness with the barramarrany by focusing on actions³⁹ with a deep and ongoing respect for including the barramarrany cultural values in the design and delivery of services. The health service partners engaged with the barramarrany cultural values by being mindful and non-judgemental of the barramarrany realities, listening, offering and then providing support. Partnering improved trustworthiness of the health service partners, and so increased trust by the barramarrany. This trust is the basis for cultural safety and is a foundation for this project.⁴⁸

The PAR action-project arose from the collective decision to restore a supportive physical and social environment by improving the functionality of the barramarrany house. Creating supportive environments is the health promotion action area that underpins the Environmental Health discipline's public health activities. In Australia, improvements in sanitation, drinking water quality, food safety, disease control and housing conditions have been central to better population health outcomes.⁴⁹ But further Environmental Health improvements are needed to achieve equity in healthy living conditions for all Australians. NSW Health has demonstrated that the Housing for Health[®] program fixes for housing health hardware can reduce the chance of hospitalisation for an infectious disease by up to 40%.⁵⁰ By fixing housing health hardware within a comprehensive health promotion framework, this PAR action-project simultaneously tackled some of the causes of poverty and the consequences of poverty.

Nutrition is well established as a significant factor in the prevention and treatment outcomes of TB.^{19,20} This is not surprising given nutrition is a basic human need and essential for good health and wellbeing. Rebuilding the vegetable garden and strengthening the barramarrany skills to plan and prepare healthy food was a step towards restoring the barramarrany physical, social and emotional wellbeing.

Interruption to TB transmission in Aboriginal families in northern NSW can help to reduce inequity in TB for Aboriginal and Torres Strait Islander people and can contribute to the elimination of TB in Australia. This TB PAR action-project enabled the barramarrany to be at the heart of the way TB care was approached with the barramarrany (not "on" or "to" or "for" the barramarrany), incorporated the social determinants of health, and used research and innovation to change the barramarrany trajectory with TB. The approach demonstrates how the TB PAR is being undertaken in partnership with Aboriginal families and communities affected by ongoing TB transmission in northern NSW is translating the 'End TB' strategies¹⁶ and Australia's Strategic Plan for Control of Tuberculosis² by applying the Ottawa Charter for health promotion⁹ to address the on the ground situation in northern NSW.

The PAR action-project demonstrates that freedom from TB can be achieved with Aboriginal and Torres Strait Islander peoples by reconfiguring the power imbalances impacting Aboriginal and Torres Strait Islander peoples. The integration of Aboriginal and Torres Strait Islander people as leaders, collaborators and partners in TB research, policy development and service provision could enable Aboriginal and Torres Strait Islander people to have a real and ongoing say in the development of policies that represent the realities of Aboriginal and Torres Strait peoples' lives and desires. Decolonising research methodologies, such as PAR, contribute to shifting the power balance towards Aboriginal and Torres Strait Islander people.²⁷ The TB PAR in northern NSW is amplifying the voices of Aboriginal people affected by TB to build new and shared knowledge between Aboriginal people and health care personnel, managers and policy makers.

How might this study benefit others?

This PAR action-project is a case study for improving housing and nutrition to address inequities in health and wellbeing with Aboriginal and Torres Strait Islander people. The health promotion approach used in this PAR action-project is applicable to TB prevention and care in other contexts, and for prevention of other conditions. Rheumatic Heart Disease (RHD), like TB, disproportionately affects Aboriginal and Torres Strait Islander people.⁵¹ And, like TB, biomedical responses alone do not reflect the nature of RHD.⁵¹

Improvements in housing and environmental conditions are used to inhibit the risk factors for RHD and the NSW RHD Program is piloting an Environmental Health Response Home Assessment and Fix project.³² This promising development offers new opportunities for collaborative approaches between clinical, Environmental Health and health promotion services to respond to the aspirations of Aboriginal people by engaging with the social determinants of health and being guided by the Ottawa Charter for health promotion.

3.2 | Limitations of this study

This PAR action-project was a case study undertaken with one family in a regional community in NSW. This case has been described here in detail to demonstrate how health promotion principles can be applied in other similar contexts. Erickson (1986) argues that grounding the particulars of a case study in generalisations enables what we learn in a particular situation to be applicable in other similar situations.⁵²

A limitation of case study research can be that the complexity examined can be difficult to represent simply.⁵³ To directly address this limitation, authorship of this paper is shared by Aboriginal and non-Aboriginal people involved in planning, implementing and theorising this PAR action-project. Authorship is also shared between people who are nurses, health workers, environmental health officers, barramarrany and academic researchers. The initial manuscript was drafted by a non-Aboriginal TB nurse. The initial manuscript

was then sent to co-authors for contributions, critique and ongoing development. The sharing, robust critique and development of the manuscript by co-authors facilitated ongoing deep discussion and meaningful dialogue between the authors about the best way to communicate the PAR action-project. It strengthened processes and stimulated further reflections and action for building mutual understandings and cultural safety within the team. This writing process meant reaching consensus on the final draft and submission for publication was a slower than other processes for writing for publication. But being slow and deliberate was necessary to reach consensus among all partners on the language and terminology and analysis for the reporting of the PAR action-project.

4 | CONCLUSION

Amplifying the voices of people affected by TB in the development and implementation of policy and programs is essential to end the transmission of TB. By enabling the barramarrany to have a real say, new and shared knowledge was created that reflects local realities and the specific local contexts in which they are played out. Engagement with all five of the health promotion action areas can be achieved by focusing on material social conditions through means that also address social "causes of the causes" of health inequities. Family-focused TB care strategies addressing the social determinants of health and actioned through partnerships built on trust assisted addressing health and wellbeing inequities that affect Aboriginal people. Ownership of TB diagnosis, treatment and prevention by the barramarrany was underpinned by the principles of self-determination, capacity building and social justice. These connected action areas are the operationalisation of the principles of health promotion for the translation of the "End TB" strategies to on the ground situation in northern NSW, Australia. Further research using methods that amplify Aboriginal peoples' voices and reconfigure power relations in favour of Aboriginal Australians is required for improved TB care that upholds the human right of Aboriginal and Torres Strait Islander people to be free from TB.

ACKNOWLEDGEMENTS

The authors thank the people of the Gumbaynggirr Nation who are the traditional owners of lands on which this PAR action-project was conducted, and we pay our respect to Elders past and present. The authors also thank all barramarrany members for sharing their experiences, knowledge and wisdom. Additionally, the authors thank Bulgarr Ngarru Medical Aboriginal Corporation, Unkya Local Aboriginal Local Aboriginal Lands Council and Nambucca Heads Local Aboriginal Lands Council, and Paul Corben Director NCPHU for supporting the PAR. Lastly, the authors thank the students and faculty in the James Cook University Doctoral Research Cohort Program for assistance with theorising the PAR action-project.

CONFLICT OF INTEREST

The authors declare no conflicts of interest.

ETHICS

Approval for the research was granted by the Human Research Ethics Committees of the Aboriginal Health and Medical Research Council (1043/14), James Cook University (H6315), and Mid North Coast and Northern NSW Local Health Districts (2019/ETH13467).

PATIENT CONSENT FOR PUBLICATION

The father in the barramarrany (WR) contributed to the preparation of the manuscript, is an author of the article and has provided consent for publication including the image of his original art. The father in the barramarrany understands that HPJA journals may be available in both print and on the internet and anyone can read material published in the Journal.

DISCLAIMER

The lead author (SD) affirms that the manuscript is an honest, accurate and transparent account of the study being reported, and no important aspects of the study have been omitted. This research has not previously been published, except as a brief abstract for presentations.

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ENDNOTE

¹ Barramarrany is the traditional Gumbaynggirr language term for family. The Gumbaynggirr nation stretches along the Pacific coast from the Nambucca River in the South to around the Clarence River in the North and the Great Dividing Range in the West. The Gumbaynggirr language term was used for this project with permission of Gumbaynggirr Elders to represent how the TB PAR that is being undertaken with Aboriginal communities is underpinned by respect for Aboriginal cultures and the inherent strengths within Aboriginal families.

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How to cite this article: Devlin S, Ross W, Widders R, McAvoy G, Browne K, Lawrence K, et al. Tuberculosis care designed with barramarrany (family): Participatory action research that prioritised partnership, healthy housing and nutrition. *Health Promot J Austral*. 2021;00:1–12. doi:[10.1002/hpja.554](https://doi.org/10.1002/hpja.554)