Using community-led development to build health communication about rheumatic heart disease in Aboriginal children: a developmental evaluation

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Abstract

Objective: A high prevalence of acute rheumatic fever (ARF) and rheumatic heart disease (RHD) among Aboriginal children in northern Australia is coupled with low understanding among families. This has negative impacts on children's health, limits opportunities for prevention and suggests that better health communication is needed.

Methods: During an RHD echocardiography screening project, Aboriginal teachers in a remote community school created lessons to teach children about RHD in their home languages, drawing on principles of community-led development. Access to community-level RHD data, previously unknown to teachers and families, was a catalyst for this innovative work. Careful, iterative discussions among speakers of four Aboriginal languages ensured a culturally coherent narrative and accompanying teaching resources.

Results: The evaluation demonstrated the importance of collective work, local Indigenous Knowledge and metaphors. As a result of the lessons, some children showed new responses and attitudes to skin infections and their RHD treatment. Language teachers used natural social networks to disseminate new information. A community interagency collaboration working to prevent RHD commenced.

Conclusions and implications for public health: Action to address high rates of RHD must include effective health communication strategies that value Indigenous Knowledge, language and culture, collaborative leadership and respect for Indigenous data sovereignty.

Key words: community-led development, developmental evaluation, health communication, Indigenous Knowledges, rheumatic heart disease

Rheumatic heart disease (RHD) is prevalent among young people in many sites of social disadvantage globally, with one location being Aboriginal towns and communities in northern Australia. RHD is a complex condition requiring good health communication to enable families to build effective health literacy for their situation.[1] Schools are a logical entry point for health communication about acute rheumatic fever (ARF) and RHD because the population most at risk of ARF – the precursor to RHD – is school-aged children.[2,3] Yet just how to approach health communication and what methods are most effective remain unclear.[4] For Aboriginal families, explanations about RHD are often provided in English by healthcare providers with high levels of western education and health training structured around biomedical ways of thinking. Uncritical use of the biomedical lens when teaching about RHD, even if simplified, can impede health communication so that messages are not understood by Aboriginal people as intended.[5] This is especially so where there is significant language and cultural difference between healthcare providers and clientele.[6,7] In the context of post-colonisation, disempowering health communication may deepen a sense of subjugation or invoke passivity.[8] Empowering pedagogies are urgently needed for RHD because it significantly impacts school-aged children's quality of life and life expectancy, while being largely preventable.[9]

> *"We want to write this story about RHD the way we want to explain it to the world."*
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> Aboriginal Language and Culture teacher, Maningrida, Northern Territory, 2018

Critical health communication strategies, which may or may not be undertaken in a school, ideally partner with local Aboriginal people, including Aboriginal healthcare providers.[10] Effective strategies should ensue from a stance of equality and be based on knowing the target audiences' characteristics such as language and cultural ways of learning. They should also take account of past social and political realities including those arising from colonisation.[11,12] Such

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approaches can position local community groups to gain new health knowledge and may facilitate locally led actions.[13]

Rheumatic heart disease refers to damage to the heart valves as a consequence of acute rheumatic fever, a delayed autoimmune condition triggered by untreated streptococcal-A bacterial infection of the throat or skin. Patients with ARF can experience diverse symptoms including fever, sore joints, rash and chorea, but many do not have cardiac symptoms (tachycardia, chest pain, dyspnoea) and may not present for medical care. Consequently, some RHD remains unidentified among Aboriginal children. Late presentations with complications of RHD are common.[14,15] Once diagnosed, ARF and RHD are managed as chronic conditions with penicillin injections every 3–4 weeks for five to ten years and sometimes longer.[16] Some children require open-heart surgery to repair or replace their damaged valves.

The evaluation was undertaken in Maningrida, a small town in Australia's Northern Territory. Maningrida is situated 500 kilometres east of Darwin on the northern coast and has a predominantly Aboriginal population of around 3,000 people. Maningrida was established as a permanent settlement by the Australian Commonwealth Government Welfare Department in 1957.[17] As is often the case in the Northern Territory, the settlement is situated on the custodial land of one Aboriginal clan-based group, with neighbouring groups increasingly co-residing over the past six decades because of government welfare and assimilationist policies. This has led to Maningrida emerging as a linguistically diverse site with at least ten distinct languages from three separate language families in current use. Maningrida is named here with the explicit permission of Traditional Owners and Elders.

Objective

High rates of ARF and RHD have been documented in Maningrida in the recent past.[18] Accordingly, in 2018, a heart ultrasound study (echocardiography) was implemented in the town to find unidentified cases among children, define the true disease burden and explore the value of this type of screening for RHD.[15] Concurrently with the ultrasound screening project, health communication activity about RHD spontaneously emerged in Maningrida's only school where the screening took place. Initially, this was a six-week project centred around the ultrasound screening but the 'Lúrra RHD project', a set of lessons developed by the school's Aboriginal language and culture teachers, evolved into a whole-of-school five-year curriculum strategy to help address RHD in Maningrida.

The echocardiography screening demonstrated the highest prevalence of RHD reported in public literature, highlighting that more than 10% of the children in Maningrida are registered for treatment with penicillin injections for ARF or RHD.[15] This is on a background of a high burden of disease recently determined via a linked data study showing that ARF episodes peaked in school-aged children (age 0 to 14 years), with 509 Indigenous cases per 100,000.[3] We report here on an evaluation of the Lúrra RHD project, a health communication initiative that commenced concurrently with the heart screening in the context of a community experiencing high levels of childhood ARF and RHD.

Methods

Conceptual frame

Community development principles and practices have the potential to empower Indigenous communities' aspirations for positive social change.[19] Drawing on this concept, we used principles of community-led development (CLD) sourced from the creative commons licensed work of 'Inspiring Communities', Aotearoa (New Zealand), for our innovative work around RHD health communication.[20] 'Place' as defined in CLD, is unique and central, and thus CLD was applicable in the project because of the importance of relationships of Aboriginal participants to 'place' in their cultural worldview, and relationships between people mediated by languages associated with specific places. Additionally, the non-Indigenous participants in the Lúrra project also had strong connections to Maningrida.

CLD is based on the premise that all communities have the ability to thrive and the principles offer a place-based approach so that the contributions of everyone connected to a place are harnessed and woven together. This enables local visions, priorities and aspirations to be realised. The participants view themselves as active learners as well as change agents.[21] CLD thus moves away from the norm of addressing outsiders' pre-defined community development agendas.[22] The CLD principles are: Grow from shared local visions; Build from strengths; Work with diverse people and sectors; Grow collaborative leadership; and Learn by doing.

Data collection and analysis

The evaluation reported here analyses qualitative data collected during all processes of creating and delivering the RHD lessons. Data were gathered in regular (sometimes daily) group reflections, participant observations, evaluator's notes, iterations of the RHD storyline, lesson plans, photographs and video footage of children's assessments. Interviews about the process and impact of the project were conducted by AM at intervals using open and semi-structured questions with each Lúrra team member, the school principal and the school nurse (serial interviews). Informal interviews were undertaken with some classroom teachers who observed the lessons conducted by the Lúrra team. Longer interviews were recorded and transcribed, and shorter interviews were handwritten. All interviews were conducted in English and, where Aboriginal language terms or phrases were used within interviews, or the evaluator was unsure of meanings, interviewees were able to clarify what they meant.

An iterative inductive analysis was conducted using the principles of CLD and feedback was provided over serial visits to the team by AM. Themes emerging during the process were discussed with the Lúrra team, with a concluding inductive analysis at the end of 2019. Findings and implications were discussed, and the opportunity was provided for Aboriginal team members to verbally deconstruct this article to enable their full participation as co-authors.

Ethical approval for the evaluation was granted by the Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research.

Lúrra RHD project participants

In early 2018, the Language and Culture Unit team working on the RHD lessons included three senior Aboriginal men, three senior Aboriginal women, a young Aboriginal media worker, the evaluator/applied linguist and a non-Indigenous senior teacher. Four of the Aboriginal team members had formal paraprofessional teaching qualifications.

Each of them had between ten and 36 years of teaching experience in Maningrida and its surrounding homeland schools. They speak four of the community languages as their primary languages, and while these are distinct languages (not related varieties of a single language), high rates of individual multilingualism ensure mutual capacity to understand one another.

Developmental evaluation

Evaluations of public health programs aim to provide evidence for further public health decision-making.[23] The main departure of developmental evaluation (DE) from other evaluation methods, including action research, is that local protagonists initiate the project and the evaluation, and the evaluator is an actor within the collective from the start.[24] Additionally, DE is a useful method in settings of complexity where innovative endeavours are being explored.[25] Fluidity, continuous feedback and reflection capture the journey rather than assessing it against pre-set indicators.[26,27] DE is suited to social niche innovations that are developed and refined by end-users. In this sense, the learning process is valued as much as results.[28] An applied linguist, AM, experienced in cross-cultural and bilingual health communication in similar settings,[10] was recruited as part of the Lúrra RHD project team at its inception and led the evaluation.

The evaluation was conducted over two years, 2018–2020. During late 2018 and 2019, several team members departed for social or ceremonial reasons. Aboriginal team members recruited replacements from the local community. A senior teacher linguist, CC, also joined the team in August 2018 and took over as senior teacher in 2019 as the first senior teacher took leave.

Critically, the team was supported throughout by the school's principal who endorsed the development of local RHD lessons and then a curriculum. The team received assistance from senior advisors in the Northern Territory Department of Education who supplied expertise in writing the languages of the Maningrida region and in curriculum development for bilingual education.

The screening and clinical teams (cardiologists, paediatricians, Aboriginal health workers, nurses and school staff) worked separately but closely connected with the Lúrra team, and results of both the screening and the lesson activities were regularly shared between the two groups. In reporting findings, participants are identified as either Aboriginal or non-Indigenous team members or other general identifiers to preserve anonymity within the small town.

Results

The results are reported in three components:

1. The process that emerged to create the lessons
2. Analysis of the work using the five principles of community-led development
3. Outcomes

Process that emerged to create the lessons

Both-ways learning

The Lúrra team used a both-ways learning process: reciprocal teaching and learning between disparate groups.[10] Both-ways learning involved a multilingual dialogical method, that is, careful, iterative discussions among speakers of four Aboriginal languages and English, accompanied by the development of and ongoing revisions to the storyline – a term referring to the sequential presentation of information, typically framed as a narrative that is a traditional form for encoding and disseminating significant information in the setting. The process aimed to produce a conceptually meaningful narrative about RHD, in that place. The discussions and iterations occurred over eighteen months (although the initial lessons were created quickly over two months). This amount of time was needed for the team to investigate and understand new and deep ideas, and to consider and decide on appropriate Aboriginal language terms, analogies and metaphors for the lessons.

Exposure to local-level RHD data

The Lúrra RHD project emerged following a presentation for teachers, including Aboriginal assistant teachers, by local nurses to explain the upcoming school-based heart screening. The presentation included community-level epidemiological data on ARF and RHD. The teachers were shocked by these data, unknown to them prior to the meeting. RHD had not been perceived collectively as a 'community problem' despite its high prevalence, likely because many children look and feel normal until the condition worsens. In fact, there was virtually no understanding of the condition among many adult members of the community, including Aboriginal members of the Lúrra team. Medical researchers had 'insider' access to the community-level data, which motivated them to instigate the screening study. When community-level data were presented to community members, strong statements were evoked around adults' universal responsibility for children's wellbeing. One non-Indigenous teacher wanted to know which children had RHD: "I didn't know there were children in my class with heart disease, that's terrible, which ones are they?"

The new information about RHD prompted the Lúrra Language and Culture Unit teachers to decide to develop a set of lessons about RHD to teach concurrently with the heart screening. In an early reflective team session, Aboriginal team members stated, "We felt it's a part of our teaching in the Lúrra to help our kids [learn] what RHD means to them" and, "We are fighting for our community hey. You know, our people. That's what we are trying you know, share knowledge to our people".

Referring to the newly revealed population data, one Aboriginal team member stated: "Rheumatic came like, came up from nowhere! But the doctors came you know, follow on that heart disease [data], rheumatic heart disease. You know that, you mob, community you know where they got information? They must have they got information from the clinic. So, that's where it started". A non-Indigenous team member also stated, "We were presented with the statistics and I suppose the breadth of the problem in the community and our Language and Culture team were reinvigorated with the need to really try and teach this problem".

Conceptual and language issues

Prior to the Lúrra RHD project, community languages had been used at Maningrida school as a distinct subject area or to deliver Indigenous perspectives on 'mainstream' curriculum. In developing the RHD storyline, community languages were used in a new domain of discourse, to discuss new topics and to develop texts in a new written genre. The storyline introduced medical science concepts foreign to traditional Indigenous culture. Developing the lessons involved the Lúrra team first learning about RHD. English language and the local Aboriginal languages have disparate historical developmental roots and highly disparate cultural histories. English proved to be a difficult 'stepping

off' language. However, an audio recording about RHD in a neighbouring Aboriginal language (developed by the evaluator prior to this project) and understood by one team member provided an effective 'stepping off' tool, clarifying the initial discussions that were undertaken in English. This team member interpreted the messages into Burarra. Djinang and Ndjébbana speakers who understand Burarra were then able to interpret the messages into their languages. Ndjébbana speakers were subsequently able to interpret the concepts into Kuninjku.

Many of the concepts central to understanding RHD are entirely foreign to local Indigenous culture and knowledges, as are ways that related concepts are represented in standard teaching texts (e.g. colour red for oxygenated blood, blue for deoxygenated blood), and there are often no direct translation equivalents in local community languages.[29] The team applied meaning-based translation methods; they explained ideas that could not be directly translated or used Indigenous analogies and metaphors. Back translating their new RHD texts highlighted misunderstandings that could then be re-worked for clarification. Aboriginal team members sought advice from Elders out of hours, "And, because it's a English word, and we couldn't understand, so we had to break it up … we asked the old people, Elders …"

Referring to this conceptual and linguistic work, one Aboriginal team member stated, "The main thing is that we want to see, teach, in an understandable way. So, there are some words that we don't have in our language, so we have to go around it, go under it, [for example] 'germs' and, it takes us a lot of hard [work] to like think and work on some of the lesson plans. The ideas to put in". And a non-Indigenous member reported, "And then, once they [Aboriginal teachers] had the story, the concepts in their mind, we went off exploring the different language terms, which is a lot of work".

A biomedical perspective was intentionally restrained by non-Indigenous team members during this early work to optimise Aboriginal team members' exploratory thinking. As different parts of the storyline emerged, non-Indigenous members (nurse and teachers) held separate discussions to determine how the emerging narrative aligned with scientific concepts. This process did not result in any significant changes to the storyline.

One non-Indigenous team member stated: "We favoured an approach that allowed the Language and Culture team to tell the story as they understood it, in a way chosen by them – which would potentially make more sense to the students as they were translating cultural concepts as well as language ones. We supported this knowing that some of the scientific detail might be lost".

Indigenous Knowledge and metaphors

Some of the analogies and metaphors included:

- The valves that move to close off openings within the heart chambers were referred to using the Indigenous metaphors of 'mouth' and 'lips'.
- Germs were described as a new, extremely small kind of parasitic 'worm' as well as using traditional notions of 'defilement' that cause other living things to decompose.
- White blood cells defending the body from invading pathogens were described using the analogy of a traditional war party of beneficent warriors whose role is to defend territory against invading outsiders.
- The analogy of roadblocks, such as the wooden poles placed across the road to warn people against entering ceremonial sites, was used to characterise interventions that people can undertake to prevent RHD occurring or progressing.

Other Indigenous Knowledge is integrated into the lessons. For example, anatomical knowledge embedded within hunting and butchering practices, traditional methods for 'eradicating defilement' (killing germs) and treating different kinds of infection such as topical application of mangrove mud; bathing in the oil-infused water of Melaleuca swamps and medicines prepared from local plants such as the green plum, *Buchanania obovata*.

Lesson delivery and assessments

Over eight weeks in early 2018, the Lúrra team developed and delivered a sequence of five lessons with accompanying activities and teaching resources all newly designed by the team. Each lesson was one hour in duration. The same content was presented to students of all ages. Students' learning outcomes were assessed during a sixth hour of class time. The main learning intention was for students to understand the ideas, rather than mastering academic skills, so oral language assessment methods were used, and students were encouraged to complete the assessment tasks speaking their home languages.

Scaling up to an RHD curriculum

The initial six-week lessons were created within a tight timeframe. Due to the successful outcomes of these lessons and the extent of the ARF/RHD problem confirmed by the screening, the Lúrra team and the school principal decided to further develop and refine the lessons into a formal curriculum matched with national education standards. The principal committed to teaching the newly developed curriculum in the school for five years with the rationale that after five years, each school-aged child in Maningrida should have been exposed to the curriculum, thus providing a source of health communication in their home languages.

The curriculum contains content tailored specifically to address local health needs and is linked to the national curriculum through the skills strands of several learning areas: Health and Physical Education, Science, Languages (the Northern Territory Indigenous Languages and Cultures curriculum)[30] and General Capabilities.[31] The curriculum was differentiated into four 'levels' to cater to different stages of child development and learning. The team produced teaching resources in four Aboriginal languages and an extended English text that can be used as a focus for teacher preparation.[32] In its final 2019 iteration, the RHD storyline and focus texts address four topics, with five lessons for each.

Analysis using principles of community-led development

The five principles of CLD were used to analyse the Lúrra RHD work.

Principle 1: Grow from shared local visions

The vision to create the RHD lessons and curriculum was motivated by aspirations among local people for the wellbeing of all children in that place. Thus, the vision was child focussed and reflected local goals. An Aboriginal team member stated, "And we came up sharing ideas and what's rheumatic heart disease mean to us. So, we came up in a good point, to make a big plan first". Growth stemming from the shared vision enabled both a sense of ownership, achievement, and also of wonder, as stated by two Aboriginal team members, "I thought there was only one germ, I didn't know there were hundreds of

germs, and some of them help our bodies" and "Explaining [in] our language to them [children] and 'cos it was their first time and they were like, 'wow' like this is how our hearts pump".

Aboriginal Lúrra team members are situated within a network of clan groups unalterably bound to certain places, either at the study site or connected geographical sites. Thus, connections between clans, and the resultant kinship relationships with children within those clans, mean that all children within the community are kin. The Lúrra team were obligated to follow kin-based protocols in the RHD activities as expressed by one Aboriginal team member, "And also, like we know each child a background, where they come from" and "We felt it's a part of our teaching in the Lúrra to help our kids what RHD means to them". Thus, intrinsically within the shared local vision, was the deep-rooted concept of shared place.

Principle 2: Build from strengths

Local Indigenous knowledge and languages were valued strengths facilitating the RHD project. Senior men on the team suggested that their cultural concept of Lúrra could provide a framework for creative work about RHD. They agreed on a description of the Lúrra concept for use in the RHD work as follows:

> The term 'Lúrra' is used in this context to represent people coming together and working collaboratively. It speaks of valuing each person and arriving at a destination together. The process used by the Lúrra Unit enables different tribes with different languages to work together as well as enabling Aboriginal people and Balanda (non-Indigenous people) to work collaboratively.

On reflecting about the use of the Lúrra concept as the foundation, one non-Indigenous team member stated, "It very much symbolises this project that we have done together...the idea is that everyone learns together and travels together. If someone falls behind, well, you don't just keep going ahead. This is a metaphor for learning, you gotta make sure everyone's together, travelling together". An Aboriginal member concurred stating, "We gotta come together and learn together, sharing this knowledge together. That's what Lúrra means; work together". In a joint meeting of the screening team and Lúrra team, one practitioner stated, "I think [this is] a really important change of direction for rheumatic heart disease in Maningrida. What we have been finding this week confirms that it is a really big problem. We keep finding more cases every day. But something has to change and, it has to change together. Not just one group coming in and saying we are going to do this but actually together".

Recognition of the value of community languages in that place, as the languages of identity and that people think in to build conceptual ideas, was important. Residents speaking their clan languages were valued as experts in their place. Additionally, having participants with linguistic training (pure and applied linguistics) provided strength for a project needing analytical linguistic expertise and familiarity with north Australian Aboriginal language structures.

Principle 3: Work with diverse people and sectors

The Lúrra RHD project fostered connections between groups and disciplines that do not normally collaborate. Rather than one discipline tackling the prevention of RHD among the children, workers from the disciplines of health, education, community development and linguistics worked together with the shared goal of children's wellbeing. Culture was a further 'discipline'. It became apparent that the Aboriginal team members carried a strong sense of their position in their clans and their responsibility for what they taught to children. The meshing of disciplines replaced any sense of passivity (due to outside control) and any sense of subjugation (stemming from power imbalance); in terms of the Lúrra frame, all worked together, as described by one participant using a fishing analogy with "some bringing the fishing net, some bringing special fruit to stun fish, others paddling canoes, so we travelled together without leaving anyone behind, and everyone looking ahead to achieve the journey's goal".

Principle 4: Grow collaborative leadership

The Lúrra team relied on leadership from senior men and women from different clan groups. While the non-Indigenous leaders on the team understood the Aboriginal societal structures to varying degrees, an overall acceptance and valuing of the multicultural and multilingual nature of the community also enabled collaborative leadership to grow within the project. Aboriginal teachers achieved their task of creating a meaningful narrative around RHD in their languages and that success, coupled with the new statistics about the size of the RHD problem in Maningrida, led to an interagency cooperative in the town where the Aboriginal teachers could now participate based on their knowledge about RHD as well as their cultural status. This led to new determinations to prevent RHD in Maningrida in ongoing work. One non-Indigenous senior teacher expressed the significance of the school RHD initiative: "But, the scale of this [RHD project] was huge. And I think that the impact that it is going to have on ways things are done in the future, it has huge potential".

Collaborative leadership also grew in teaching/curriculum partnerships, with expert assistance received from senior advisors in the Northern Territory Department of Education in curriculum development for bilingual education. Critically, the team was supported throughout by the school's principal. Additionally, the Aboriginal teachers desired to further expand their influence. As well as discussing new RHD information among their social networks in Maningrida, the team had a sense of reaching out to neighbouring Aboriginal communities with whom they have cultural connections. One Aboriginal teacher stated, "We don't want them to wait five years to find about this sickness. We can make it quick for them … the right story and how to teach it and how we used activities and songs, game, and design competition". Another stated, "We want to branch it out to other people". Growing leadership is expressed in the following statement from an Aboriginal teacher, "We want to write this story about RHD the way we want to explain it to the world".

Principle 5: Learn by doing

Lúrra team members acquired new knowledge in order to effectively teach concepts to the children. Through developing the RHD storyline and teaching it they had the opportunity to learn alongside the students. A sense of achievement was apparent in a team member's statement: "I was excited to learn how to explain to the kids. It's the first time I understood this disease". Another Aboriginal teacher reported, "Lots of parents were in class; for the first time we saw four or five parents. They asked questions and we said that we were only just learning ourselves".

Outcomes

Assessment of students' learning outcomes following delivery of the initial five-week lesson plan, captured on video, indicated that they had understood much of the information that was presented. Two Aboriginal Lúrra members stated, "When we asked what they learned, they remembered because of the sequence. We got shocked as the kids reported in Burarra what they had learned the week before. They came up with all the things they learned".

Serial interviews with the school nurse revealed that the initial set of RHD lessons had resulted in some new behaviours among some school children; children began to present for treatment of skin sores, and some showed improved coping with their regular painful RHD injections. The profile of the school nurse was raised in the school. She reported that classroom teachers showed a new understanding of the importance of regular injections for their students, and stated, "The kids are yelling out my name. Even though I've not done anything or met them personally, and doing their health screen, when I am walking across to get other children they are yelling out, "Hello [nurse's name]".

Some impact was noted within the healthcare service with one community nurse stating, "I have changed the way I do that [health communication] based on the stuff I picked up from Lúrra". When asked what she changed she replied, "I talk about people's immune system attacking the doors [valves] because they look the same as strep germs".

A significant impact of the project was the Aboriginal Lúrra team members' natural dissemination of the new RHD information via spontaneous interactions within their social networks. In reflective sessions, team members reported discussing germ theory of disease with family members, opening discussions about the existence of germs, how they spread and their potential to cause sickness. One team member reported, "Yesterday my son he had a lot of sores – I told him you might get rheumatic heart". They are informing other community members about knowledge underpinning western medicine. One team member reported that his family's response was one of disbelief: "I told my family about those germs and they don't believe it. They think it's a made-up story". His statement demonstrated that people in his language group were discussing the new information, despite not yet believing it.

Further evidence of story dissemination was provided by a team member whose relatives read the Lúrra team's RHD information posters produced in four languages and displayed around the community. The relatives had pointed out a single spelling mistake. The team member was simultaneously embarrassed that someone had found a spelling error and delighted that members of his language group had paid close attention to his work.

During a team discussion, one Aboriginal team member noted that among members of her language community there is acceptance of the existence of micro-organisms and their potential to cause disease, but there are debates about their ubiquity. She had pointed out that germs multiply quickly and can spread by touch from person to person. In reply, one person stated, "There are no germs on me, because I shower and put on clean clothes every day". These social network conversations provide evidence that sections of the community were already having debates about reducing the likelihood of infection by reducing the number of germs on their bodies and avoiding transmission.

A new network of local agencies formed in response to the screening and the new RHD health communication produced by the Lúrra team. In ongoing meetings, this group hopes to undertake initiatives that will help to reduce the rates of RHD in Maningrida.

Discussion

Developing effective health communication

Persistent poor health in Aboriginal communities generates an intense mandate for reform in health communication as one component to improving health and calls for strong multidisciplinary effort. For Aboriginal people whose home language is not English, such as people in Maningrida, scientific information about disease causation is not in their cultural repertoire. It remains largely inaccessible, new information that must be unpacked in an empowering way.

The Lúrra RHD project revealed some of the complexities of providing health communication in a multilingual and cross-cultural setting. It highlights the types of human resources, shifts in control, time and methodological approach that are needed to undertake the development of effective health communication.[33] In this instance, a community-instigated and community-led health communication agenda was effective and the use of DE to evaluate it was appropriate. The depth of the process and time required for the project provides insight into why past attempts to teach broadly about RHD in settings like Maningrida may have lacked impact. To understand the RHD story requires unpacking 'inside' knowledge from deep within the biomedical domain while aiming for maximum understanding in the local linguistic and social context.

The process of developing a coherent storyline, curriculum and teaching materials involved providing adult language speakers with access to learning resources and opportunities for discussion that continued until they were able to describe the health condition accurately in their own words. This was an empowering process due to its participatory nature and valuing of community languages and cultural knowledge, which in turn grows collaborative leadership. This contrasts with generic, 'one size fits all' population messaging, especially where messages are produced by people outside the language and cultural group. Previous studies have shown that generic health communication has limited effectiveness in cross-cultural situations due to poor use of Indigenous languages – the languages in which people think.[7,10] Typically, health messages are delivered in English and the information they contain has been simplified as though for delivery to a small child; whereas adults, especially parents, have the right to receive adequate information to understand the medical issues.

Growing collaborative leadership

The vision for the Lúrra RHD project originated within the Lúrra team, which consisted of senior men and women who held leadership positions both within their workplace and their cultural community. A true sense of collaboration and shared leadership characterised the development of learning materials and the implementation of the lessons in the school. This model helped to ensure that the project was not perceived as an external program, but rather as a shared project with genuine local leadership.

The term 'community engagement' is used frequently in both health promotion and marketing, but in Aboriginal community contexts, it more often describes endeavours to present information or introduce projects originating outside a local community.

Despite best intentions, directing efforts to a community with this stance can be disempowering for Aboriginal residents and may lead to disengaging, a weariness of outsiders' projects, or passive resistance. Different approaches are needed to effect changes.[34] We suggest making the term 'community engagement' redundant in the Aboriginal community research context and replacing it with more inclusive and participatory language to raise the likelihood of benefit to both outsiders and insiders along paths to change. A term such as 'collaborative leadership' captures this intent and removes the notion of outsider's authority based on *their* knowledge, to a focus on a community of people with whom outsiders need to work meaningfully and collaboratively. It removes the outsider's task of seeking cooperation. It evokes a sense of sharing and freedom to address an issue in ways that build on strengths and can mobilise Indigenous Knowledges.[35,36] Effective innovations in health communication and knowledge sharing in Aboriginal community settings are likely to be incremental, and cumulative in impact, capitalising on local social communication networks[8,10,13] and growing opportunities for local leadership in responding to health issues.

Importance of community-level data for Aboriginal groups

Prior to the screening study at Maningrida, RHD was not perceived collectively as a 'community problem' despite its prevalence. When community-level data were presented to members of the community, they were galvanised into action. Identified data on who has ARF or RHD has been collected by the Northern Territory Department of Health RHD Control Program since they started a disease Register in 1997 and, while the provision of a Register has been shown to be vital for ongoing disease control, community-level data does not often reach people reflected within the data. Aboriginal community residents and leaders may not know that this data exists because it is collected primarily for health service and research purposes.[37] Most people listed on the Register are Aboriginal. We believe that respect for Indigenous data sovereignty should result in an intentional approach to the provision of de-identified community-level RHD data to leaders in Aboriginal communities.[37] In two sites in the Northern Territory, one being Maningrida, access to community-level RHD data has galvanised local leaders to intensive action, indicating that this is a critical component for health communication and action in this setting.[10]

Effectiveness of developmental evaluation

Aware that this was the first time that an attempt had been made to co-design and deliver western medical information in the medium of community languages, the Lúrra team decided to document the progression of their project. Flexibility in the team's approach was matched by the flexibility of the DE method. Indeed, the team expressed a sense of expectancy in both what they were attempting and the way it was being captured. DE was suitable for the Lúrra RHD project because of the complexities of the context, characteristics of the participants and novelty of the activity. Participants included people with diverse skills from different disciplines, speaking five different languages, as well as Aboriginal children whose first language is an Aboriginal language, and who learn English as an additional language at school. The project addressed a complex disease in a post-colonial, racialised, cross-cultural, multilingual and institutional (school) setting. In looking back, we determine that the essential elements for DE were present as described by Quinn Patton (2016), that is, the purpose of the task was to create something new in a niche context, the focus was on the use of the end product, there was recognition of the complexity of the task within complex systems (school, community and cultural), and there was co-creation and timely feedback.[25] DE enabled real-time reflective discussion about whether what was being done was working, and why or why not. We consider that DE in the context of this study also enabled the timeliest evaluation approach. This is important due to the urgency of the public health issue of RHD among Aboriginal children in northern Australia and the transferability of the curriculum to other communities with similar traits to Maningrida.

Study limitations

In Aboriginal society, as in many other societies, children do not control their living circumstances, meaning it is critical to teach adults about RHD. Permission to interview children was not requested due to the complexity in the ethical conduct of research with children and limitations in the timeline of the evaluation. Time pressure was a limiting factor in the RHD storyline and curriculum development due to teachers still needing to carry out usual work activities.

Conclusions and implications for public health

An effective method was used to evaluate a novel, school-based project that used the principles of CLD to address RHD in Maningrida through language-based and culturally relevant health communication. Action to address high rates of RHD in this and other Aboriginal communities must include effective health communication pedagogies that value Indigenous Knowledge, language and culture, collaborative leadership models and respect for Indigenous data sovereignty. The Lúrra team's experiences included wonder, a celebration of their progress and spontaneous sharing of new knowledge within natural social networks. These components, evident in the evaluation data, indicate that the methodology was empowering and effective for the setting. The principles of CLD proved to be a feasible and effective framework for tackling such a complex health problem. Community work is continuing in Maningrida in a collaborative manner and further studies will determine the effectiveness of RHD prevention strategies in this place.

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Supporting Information

Additional supporting information may be found in the online version of this article:

Supplementary Figure 1: The Lúrra logo. Permission to use this framing for the project was granted by senior men in the Lúrra team who are both traditional owners of the clan land on which Maningrida community is situated and custodians of local Indigenous knowledge. The Lúrra concept is not used in its entirety here; deeper restricted knowledge is held by custodians.

Supplementary Figure 2: A student's conceptualisation of a white blood cell fighting a bad germ, 2018.

Supplementary Figure 3: A student's use of metaphor of a fish trap depicting how white blood cells know good germs from bad 2018.