Meaningful research in Australian Aboriginal communities, whether remote or urban, is hard. There is often tension between the world view of Aboriginal people and the academic demands of research. Ideally research should be led by Aboriginal people, but it may be difficult to find people who have seniority in the community and the necessary research, clinical and literacy skills for these leadership roles. The role of the Aboriginal researcher is complex, but critical to success. Aboriginal research team members should shoulder responsibility for the research and the actions of the research team in the community, requiring a large amount of trust and commitment from them. The practical problems of conducting research in remote communities may be at odds with the procedures and policies of academic institutions. These issues can be difficult to overcome, but not impossible if sufficient commitment is given to developing relationships and engaging fully with the community. It takes time, often many years, but the rewards for the community, the team members and for research organisations can be great.

The Western Desert Kidney Health Project (WDKHP) was conducted in the Goldfields of Western Australia between 2010 and 2014. The WDKHP was developed to investigate the factors contributing to, and associated with the high rates of type 2 diabetes and renal disease in the Goldfields. At the same time, the aim was to develop research skills in the community, while developing community capacity to combat these diseases and contribute to Pulkurlkpa – a deeply soul-felt sense of joy, hope, optimism and resilience.

Chief investigators A and B for this project are embedded in the community – they are sisters in law. CIB is a senior woman of the three main tribal groups for the region – the Wongatha, Mulba-Ngadu and Anagu tribes. She is also an accomplished and well known musician and artist. CIA is not Aboriginal and is a doctor. The third member of the development team is a senior Community Arts practitioner, who, although not living in the Goldfields, has long relationship with the community. This team has been working together in research and arts in the region for more than 20 years. The idea for the WDKHP began as a series of conversations at funerals – funerals of community members who had died from renal disease, diabetes or associated complications. The leading cause of avoidable mortality for Aboriginal people in the Goldfields of Western Australia is type 2 diabetes. The demand from the community that something be done to prevent this loss of life and potential was brought to our chief investigators as community members with skills and knowledge.

During development of the proposal CIB visited every community to ensure wide consultation, in accordance with cultural protocols, and to invite participation. Her cultural standing along with her research experience in this community meant that she was able to identify and talk frankly to senior community members and elders about the difficulties, cultural and practical, in undertaking such an extensive project, and they made meaningful input into the study design. Consultations occurred around campfires, in kitchens over cups of tea, at social events, arts workshops and at formal community workshops.

The community consultations identified stress as a very significant factor in poor health and in the development of unhealthy lifestyle practices. Stress was seen to be multifaceted, but largely contributed to by a burden of grief, guilt, anger, frustration and bitterness that many people carry. The high levels of stress seemed to contribute to poor motivation and lack of resilience in the lives of many Aboriginal people and communities. There was a lack of ‘Pulkurlkpa’.

The concept of ‘Mara Yungu’ was important in the study design – this roughly translates as ‘to offer your hand’. It has many overlapping meanings – it can mean the way you offer your hand when meeting someone for the first time, which for the Goldfields and Western Desert tribal groups, also implies an opening of your spirit and a sharing of trust. It can mean offering your hand to help someone, that is ‘giving someone a hand’ and it describes the process of two-way learning where people contribute different skills or knowledge to solve a common problem.

The delivery of the key health messages needed to be fun, exciting and empower participants to find innovative ways to overcome the challenges to healthy behaviours. Many of the changes would require not only personal, but systemic change. An innovative approach and a highly skilled team were needed. Team members (research staff and artists) had to have sensitivity and skills to be able to work with children and communities that may have suffered significant trauma. They needed to be able to work within the complex ‘skin’ system. Aboriginal team members had to be respected community members who could negotiate the subtle and demanding cultural considerations, complex kin relationships and who were also skilled health workers and artists. They needed to be open to mentoring and working with the non-Aboriginal members of the team. All team members needed to be able to live and work together, juggling family and community responsibilities while away from home for weeks at a time. They needed to be flexible and able...
to cope with the dynamic nature of life in remote areas with changes in weather, in community priorities and within the team, able to change the process as the need arose. Partnering with an Aboriginal Community Controlled Health Service and an Aboriginal community based arts and cultural organisation allowed us to have a core of two Aboriginal researchers – one male and one female, and a pool of other appropriate Aboriginal researchers who rotated through the team. The team was complemented by artists, medical students, volunteer researchers and doctors (paediatric registrars) who received invaluable cultural mentoring from the Aboriginal team members and in turn supported the Aboriginal researchers in literacy and clinical skills. Non-Aboriginal team members were introduced to the community as friends by well-known and respected Aboriginal researchers who were also community members – immediately giving them family and ‘skin’ status. The great strength of this project was the coherent patchwork of people with a wide variety of skills, led by a senior and experienced Aboriginal researcher. As one of the artists expressed it:

Even if you have never worked with an Aboriginal community before, you are able to cope as you’ve been shown, you know how to present your hand properly.

**What Did It All Look Like?**

The WDKHP team spent about a fortnight in each community annually for 3 years, collecting data on health status using a mobile clinic truck equipped with point-of-care machines. These machines were important in addressing the cultural concerns about collection and use of blood and body fluid samples – all samples were consumed by the testing and then disposed of, no samples were sent away or stored. Extensive history was collected from participants and recorded on paper data sheets, usually in a private but open air environment. This was considered important as it demonstrated privacy without secrecy. (Fig. 1 Photo Roman Kutzowitz – data collection occurred in the open air in private, but not secret settings.)

**Phase 1 – Getting the Messages Across**

The first priority was to get the health messages into a form that would be suitable, attract the interest of community members and support cultural identity and pride.

Community arts has community participation and dialogue at its core, we had used it successfully for many years. We chose it as the vehicle for community development, engagement, education and to support the development of resilience. It allowed us to address many issues that would otherwise be beyond the scope of the project and allowed for meaningful reciprocity as well as opportunities for Pulkurlkpa.

On advice from senior Aboriginal community members, we used the traditional sand drawing technique of Milbindi to explain our plans and the health messages. This technique lent itself to animation.

Senior animation artists, with extensive Community Arts experience, were engaged as artists in residence to focus on the children, working through the schools. The Aboriginal researchers brokered culturally sensitive stories, incorporating the key health messages and assisted the visiting artists to identify key community participants, who had cultural authority, who could oversee the arts activities. The children transformed the story into an animated movie using images drawn in sand gathered from their own community (Parna – our country). The stories reflected unique features of the community and translated the health information into a form relevant to each community. At the end of each residency the whole community was invited to the movie premiere, the results of health screening were presented and a healthy supper was served. The creators of the animations were applauded and celebrated.

**Fig. 1** Photo Roman Kutzowitz – data collection occurred in the open air in private but not secret settings.
Phase 2 – Building Capacity

The focus in phase 2 was to consolidate messages and to build capacity and problem solving skills. Sculpture, music and dance were the mediums used to demonstrate innovative approaches to a problem and a stepwise process to achieve an outcome. In one community the children learned how the kidney functions to filter the blood – so they designed and built a water sculpture demonstrating the important filtering elements (Fig. 2 Photo Matt Scurfield – Kidney Water Sculpture). In another community, where many children reported feeling ‘invisible’ and where there had been a number of youth suicides, they designed and created aprons showing how kidneys work and then wore these aprons as part of a portrait photography experience demonstrating ‘How amazing I can be’ (Fig. 3 Photo Matt Scurfield – How Amazing I Can Be – soft sculpture taught skills in innovative problem solving as well as the arts). Choice of art form was decided after consultation with community members about what would be most suitable for their community.

Phase 3 – Helping the Community Find Its Voice

Change in health behaviours, especially diet, requires major effort and community structural change. An important aspect of the project was to equip community members to advocate for change in their own communities. Singing, especially choral singing, was chosen as the medium because of the health benefits of singing, to give community members the skills and confidence to speak up for their communities, and to build the sense of community and shared purpose. Choral singing has a long history in Aboriginal communities and there was great enthusiasm in the community forums for it to be included.

An internationally recognised Choir Master, accompanied by CIB, spent several days in each community conducting singing workshops, with particular focus on the children. Community members then rehearsed by themselves over 6 months. The WDKHP field work culminated with a public performance by the choir, presentation of results to the community and a celebration in the major regional town. (Fig. 4 Photo Matt Scurfield – Turlku Birni Choir Performance).

Did it Work?

Participation in the study was a marker of success of the engagement strategies. Almost 38% of the total population in the study communities, including 80% of the Aboriginal population (n = 1115) enrolled and participated in the study. In some communities, there was 100% participation. More than 2000 people, including all the children in the 10 community schools (n = 1300), took part in the arts activities either as workshop participants or audience.
We used a number of different strategies for evaluation of the project – measuring change in health measures over time, questionnaires administered at the time of each data collection, participant observation strategies, targeted interviews and an innovative project using participatory video making. The evaluation strategies and results are reported elsewhere, but in summary, there was only positive feedback from the community except for expressions of dismay that the project was limited to 3 years (Fig. 5).

There was clear demonstration of the absorption of the messages in the changes observed in the communities. Communities have been able to use the health status information, knowledge and support provided by the WDKHP to advocate for their communities and achieve change – all five towns now have a grocery store with an emphasis on fresh foods, prior to the study fresh fruit and vegetable supply was poor and two towns had no store. Two towns and two communities have planted fruit trees in public gardens. All of the remote community schools and most of the town based schools now have new fruit and vegetable gardening programmes.

Wider recognition has been very important in providing kudos and pride for the participants and the communities. The artworks produced during the project demonstrate how the key health messages have been absorbed by the children who created them and communicated to a wider audience. The sand animations particularly demonstrate the translation of the key health messages and have received critical acclaim. They have been widely viewed, via the website (http://www.westerndesertkidney.org.au). ‘Alfie the Tooth Fairy’ was awarded the MJA Ross Ingram Memorial Competition Prize in 2011 (http://youtu.be/qSGgYIdiai0).

The Choir Project has led to the formation of an ongoing choir for the region. The choir was invited to perform at major national arts festival in 2014 (The Fairbridge Festival and the National Regional Arts Summit). Several of the young choir members have been offered places in highly competitive tertiary music and performance courses. A skills development programme is being developed with a tertiary college of the arts to be delivered to the children in the region annually.

The WDKHP was awarded ‘Good Practice’ recognition by Creative Partnerships Australia, a national competitive programme, in 2013.

So . . .

Life in Aboriginal communities can be a rich and rewarding experience if children have resilience and are able to make the most of opportunities.

Community arts is a joyful, exciting and engaging method for health promotion, community development and the development of resilience, especially for children. This method can be used to provide immediate, meaningful reciprocity in community based research.
Despite the arts residencies being quite short in the scale of our participants' lives, they still had potential to contribute to resilience in participants because of their novelty, their intensive nature and their focus on doing something important that would have wide benefit not only for the community, but for a much wider audience, and the kudos and recognition they bring.23

The most important question is probably the most intangible and hardest to measure—did we bring Pulkurlkpa? During the WDKHP we have seen individual and shared joy from participants and research team members. The activities were fun to do, they brought the joy of discovering new talents, especially for the children, the joy of achieving something, the joy of making something and sharing it with others and the joy of recognition from friends, family and the wider community. From joy comes optimism and hope—the essence of Pulkurlkpa.4 The fact that we cannot quantify and test this for statistical significance makes it no less real, or important. Examples of this wonder and joy can be seen on our website (http://www.westerndesertkidney.org.au). Whether this will translate to lasting health benefits will be the subject of other papers and may take many years to determine.

Developing long-term relationships with Aboriginal researchers who are embedded in the community, have cultural authority, who understand the cultural nuances and are able to engage the community leaders is critical to research and likely to bring Aboriginal and non-Aboriginal researchers a greater sense of personal Pulkurlkpa.

Ethical approval for this project was given by the Western Australian Aboriginal Health Ethics Committee and the University of Western Australia Human Research Ethics Committee. All participants gave their informed consent for participation and specific consent for the publication of images.

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Aboriginal images by Theresa Matta (10) from Operation Art 2014.