Conducting research together with remote Aboriginal communities

Emily Fitzpatrick¹, Annette Kogolo²
¹Sydney University and Sydney Children's Hospital Network, ²The Picture Talk Project

Abstract

Introduction: An international systematic literature review found that few publications evaluate the preference or understanding of an individual or group when seeking consent for research with Indigenous communities. Research with Indigenous communities has not always done in a way that address the priorities of the community, even if they are conducted in line with protocols such as the NHMRC guidelines. The Lililwan Project is an example of a study that was well received by the Aboriginal communities of Fitzroy Crossing receiving a 95% participation rate. In response, the community initiated the Picture Talk Project, to examine what had been learned about community engagement and consent process. In this paper we will discuss how findings inform current research policies and ethical guidelines.

Methods: Invited by Aboriginal leaders of the Fitzroy Valley, researchers with the Picture Talk Project interview Aboriginal community leaders and focus group discussions were held with Aboriginal community members about research experiences and the consent process including the methodology used by the Lililwan Project. These are analysed using NVivo10 software with an integrated method of inductive and deductive coding and grounded theory. Local Aboriginal research team members, employed as Community Navigators to interpret language and provide cultural guidance, also validate the coding of data. Themes are synthesised and supporting quotes from participants were identified. This paper will explore three themes in the light of how they inform policy change.

Results: Interviews with Aboriginal leaders (n=20) and focus groups (n=6) with Aboriginal community members (with 3 to 10 participants) were conducted in the presence of a local Aboriginal Community Navigator to interpret language and provide cultural guidance. Participants were from different age groups, both males and females and from all major local language groups of the Fitzroy Valley.

Themes include:

- Research—finding knowledge
- working together with good communication
- being flexible with time.

Insightful statements from individual participants exemplify these themes. Recommendations for research policy change are put forward based on these findings.

Conclusion: Research policies and guidelines need to change so that researchers rethink the ways in which Aboriginal people are approached to engage in research. Respect for cultural differences needs to be better understood so that it can be embedded in every step of a research process. Aboriginal research partners should be engaged from the start to the end of any project. There needs to be flexible timelines provided by funding bodies if a project is delayed for cultural reasons. Projects should specify how they aim to provide benefits to the community.
Introduction

When starting the conversation of potential research with Indigenous communities, researchers have not always set out on the right foot. Our international systematic literature review found that few publications describe in detail the methods used to seek consent for participation in research with Indigenous populations and even fewer researchers report evaluating the preferences of how research information is presented and whether it is understood by potential participants. Research with Indigenous communities has not always responded to community-identified priorities nor accommodated local Indigenous cultural protocols. The Lililwan Project was an example of a study that was well-received by the Aboriginal communities of Fitzroy Valley. This was a fetal alcohol spectrum disorder prevalence study, initiated by community leaders of the Fitzroy Valley, who invited researchers to collaborate in partnership and consult the wider community to confirm that this was a priority. Local community members were employed as Community Navigators to interpret language and culture throughout the research process. The Lililwan Project was so successful that it obtained a 95% participation rate and was highlighted as an example of ethical research in the 2010 Social Justice Report. To reflect and learn further from this response, leaders of the Fitzroy Valley community invited the Picture Talk Project, to examine the community engagement and consent process. In this paper we aim to translate findings into recommendations for changes in ethical guidelines for research and policies. The project was named by MH of the Walmajarri language group, based on the pictorial flip chart used as a visual aid when seeking consent for the Lililwan Project. It must be noted that this paper will use the term ‘Indigenous’ when referring to all populations of Australia or the world that are considered to be Indigenous. Terms such as ‘Aboriginal’ or ‘Torres Strait Islander’ or language group name such as ‘Bunuba’ will be used as preferred by the community.

Methods

Forming partnerships
The Picture Talk Project research team is comprised of JO, MC and TL who are Aboriginal leaders of the Fitzroy Valley; as well as HD’A who is an Aboriginal researcher for the Menzies Institute, Darwin who is originally from the Kimberley; university-based medical professionals EE and EF; public health researcher AM, anthropologists GM and CH. In addition, Community Navigators were employed on the research team to translate and interpret as well as provide cultural guidance. These are Aboriginal people held in high regard locally, and whose own cultural knowledge was strong. The Picture Talk Project was designed together by the research team to be culturally appropriate through embedding local Aboriginal protocol into the research practice and scientifically rigorous through using evidence based qualitative research methodology.

Population
The Picture Talk Project was set the Fitzroy Valley, the Kimberley, in the far north of Western Australia. This region has a population of approximately 4500, 95% of which are Aboriginal. Access to the more remote communities of the Fitzroy Valley are cut off annually by flooding from the ‘Wet Season’ from December to March. The Picture Talk Project participants are Aboriginal leaders and Aboriginal community members who are parents and carers of children of the Fitzroy Valley; both male and females over the age of 18 years from all of the main language groups of the Valley, namely: Bunuba, Walmajarri, Wangkatjungka, Gooniyandi, Kija and Nikinya language groups.

Community engagement
The Picture Talk Project was introduced at a number of meetings around the Fitzroy Valley. Through this process, community members were able to give advice and feedback on how the project should...
run. Aboriginal community members were invited to approach EF or a Community Navigator to ask questions about the project or volunteer to participate. Initial community consent was granted through acceptance at the community meetings, however it is an ongoing process, and EF continually verifies community approval of the project by visiting the Kimberley in person and through phone-calls and emails throughout the research process. A project logo was designed with a local artist NC and Community Navigator SN with a motto representing the spirit of the project: ‘Working together, learning together, knowing together’ (See figure 1). Aboriginal leaders on the research team explained that a logo was important so the researchers could have a visual identity around the community.

Figure 1  The Picture Talk Project Logo and Motto

This logo was designed to represent the main language groups of the Kimberley. The river is crossing the highway representing the meeting of the Aboriginal world with the Western world. The black band represents local Aboriginal people protecting the country of the Fitzroy Valley. If researchers wish to work with Aboriginal communities of the Fitzroy Valley, they should work with local Aboriginal people throughout the research process.

Recruitment
Some participants volunteered to be involved with the Picture Talk Project after the community presentations. Aboriginal community leaders were recruited through purposive sampling as directed by the Picture Talk Project research team. Aboriginal community members were recruited through snowball sampling. Avoidance of the research team was taken as refusal to participate. This was verified by the Community Navigators through reading the individual’s signing or checking with them privately later. Avoidance has been shown as a way of declining consent in other Aboriginal communities of Australia. Even if the community consented to participate, they were respectful and supportive of individuals who did not wish to be involved.

Individual consent
Once community was happy for the research to go ahead, the researchers were permitted to seek consent from individuals to participate. Community Navigators interpreted and explained the participant information statement and consent form. Participants were given the option to provide written consent or witnessed verbal consent. Following this, they were asked to fill in a small survey about their demographics. It was made clear that their participation was confidential and that they had a right to refuse to take part or withdraw at any time. Participants were given the chance to nominate where and when they would like the research to take place. Interviews and focus groups were either voice-recorded or hand written by EF at the time and typed into MSWord later.

Data collection
This qualitative research project interviewed Aboriginal community leaders about the community engagement and consent process. The Picture Talk Project also held focus groups where Aboriginal community members participate in discussions about their experiences with research and the individual consent process. It is reported in line with the COREQ guideline for qualitative research.

Interviews and focus groups were conducted in a semi-structured format, designed to be flexible. Questions would be asked based on what participants said, or where the flow of conversation was
going. EF would refrain from interrupting the silence that sometimes followed, giving time for participants to process the question and formulate an answer. All responses were encouraged, especially if information was being shared through telling stories or ‘yarning’.

Data analysis
Interview and focus group transcripts were typed into MSWord which were subsequently uploaded into NVivo10 Qualitative Software and coded line by line in an iterative process. Grounded theory was applied with inductive and deductive coding. A code hierarchy was formed and themes were synthesised. Major themes capture the issues that were raised as important to the Aboriginal leaders and community members of the Fitzroy Valley. Rich quotes were sourced to exemplify these themes. Interviews were coded separately to Focus Groups. This paper will report and analyse three of the major themes from the interview analysis in light of how they inform recommendations for policy change.

Results
Interviews with Aboriginal leaders (n=20) were conducted in the presence of a local Aboriginal Community Navigator to interpret language and provide cultural guidance. Participants were from all of the major language groups: Bunuba, Walmajarri, Wangkatjungka, Gooniyandi, Nikinya and Kija, both males and females and from all ages over 18 years. Of the participants invited or asking to be involved, there was 95% participation rate. One leader declined, as he did not have time to participate.

Research was conducted in a variety of places from offices to sitting in the front yard of someone’s house. These settings were determined based on what was the most convenient or preferred setting of the Aboriginal community leader.

The themes discussed in this paper are:

- Research—finding knowledge;
- Working together with good communication;
- Showing respect for Aboriginal people and being flexible with time

Research—finding knowledge
The main theme discussed by both Aboriginal community leaders and focus groups was ‘Research’. This topic was directed by the initial questions of the interviews and focus groups, asking participants what their understanding and experiences are with research:

“Each of the language groups will have different names or terms in each of the languages about asking questions, about talking, about explaining. So there’s no one word because research to me is more than just asking questions.” (Participant 18)

The ‘researched’. When talking about some research experiences, there was a sense of lack of ownership and consultation with the community:

“In the past I don’t think people who were doing the research felt they had to consult with Aboriginal people…When you think of researchers… going on for years on Aboriginal people. We’re the most researched group in this country and yet nothing’s changed. I believe that if you’re going to do research we should see changes or we should benefit you know.” (P17)

“Well look there’s been a whole history of Aboriginal people just being subjects of research and there’s been hundreds of stories of where we’ve been subjects of research. People have gone away and written about us, it’s their perspective, their views and you know it’s written in
research language, so academic writing sometimes it’s written in foreign languages so we don’t understand it.” (P18)

“It’s really common sense but with research they tend to just come in and disregard all that cultural knowledge and local information or there’s no respect for having Aboriginal leaders in the Valley that have that authority and that knowledge. “(P17)

**Researching together.** There are some positive stories of research where the design of projects were more inclusive and addressing community priorities:

“I’ve seen a lot of research… there’s only one research project that I think we’ve benefited from and that’s the Liliwan project.” (P17)

There was some direct feedback for the Picture Talk Project about why it is meaningful to the community of the Fitzroy Valley:

“I think.. your project is going to help in informing and empowering local people and those researchers that may come to communities like the Fitzroy Valley region and participate in good… areas of research.” (P18)

**Working Together with Good Communication**

Research projects should be designed together with local Aboriginal community members from the outset. For this to happen, respectful, trusting relationships should be established:

“Building the relationships with people… investment in relationships is critical to any research (project) and then once you’ve established relationships then people are able to inform and guide you to the right people.” (P18)

External researchers should work with a local Aboriginal person who is respected by the community:

“Local respect, like (someone) they know… You’ve got to be really aware of the person you choose. Someone who lives with those people. You can’t get someone saying I know a few friends. My mates from that community, I’ll take you out there and get in there. No, people will pass that person. They will look at his background history and they will look at him. You need.. the respect, you know? The community respect.” (P8)

This partnership will support research design so participants might respond more openly to questions:

“There are questions around respectful questioning. How do you frame your questions so that they’re not seen to be disrespecting or insensitive and who, if there’s a focus group, who are these people and what are their relationships to each other because questions asked of one person may be something that’s inappropriate to…another member of the focus group.” (P18)

Community leaders explained that it was marked as a sign of respect to be consulted and involved in the initial discussions of a project:

“Talk with the people first and respect them. Just don’t do it your own way.” (P5)

Ensuring that external researchers continue to communicate with the community about research progress and findings was considered very important:

“Communities are tired of researchers coming in and out and having no accountability back to the community.” (P18)

When referring to the Liliwan Project:

“I was really pleased that we were able to participate and really shape that research project so that everyone who should be involved were involved and it was done in culturally appropriate way.” (P17)
**Being flexible with time**

It is important researchers are permitted to work around more flexible timelines while working in remote Aboriginal communities of Australia. Aboriginal communities have many competing priorities and major events such as a cultural trip to go to the desert might take priority to a research project. Researchers working in remote areas need to be flexible and understanding of such things:

“If you want to do research, you can’t just set a timeframe because you’ve got to be respectful of what’s happening around you” (P20)

“They know you’ve got your work but what about our side of work, you’ve got to show respect, show respect to their side.” (P8)

Sometimes it will take longer than expected for a community or individual to consent to a project. It might take more time to explain what it is about in a number of different ways before people understand enough to feel comfortable to take part:

“To be able to get people to benefit, it also has to make sense to them, and to make sense to them is.. to try and get people to understand what it is that you are trying to do and you’re all moving together so it’s patience really. Nothing happens overnight.” (P20)

It is crucial for researchers to be sensitive to cultural priorities such as “Sorry business” (mourning period):

“Those people on the sorry side, you’ve got to pay respect to them, don’t get them involved with anything.” (P8)

This period of time is nominated by the family. It is important that the family member’s name is not mentioned out loud to those on the sorry side.

**Discussion**

When talking with Aboriginal community leaders of the Kimberley about research, it is evident that external researchers should be required to consult the community about what area is in need of research. External researchers should be required to detail how a study provides benefit to the community they are working with. Researchers are often restricted in their scope based on their funding source. Thus the first policy recommendation we make is:

1. Research protocols and ethical guidelines for research with remote Aboriginal communities should require research funding bodies and external researchers to be responsive to the research needs identified by the communities.

The language of inequality that is still prevalent today needs to change\(^1\). External researchers should engage differently with people living in remote Aboriginal communities\(^1\). A local Aboriginal person who has local respect and of the right language group is needed to introduce them to the community and guide them through cultural protocol throughout the research process. This person should also be given the title of researcher. The subtleties of cultural relations are often missed and failed to be acknowledged by people who have little experience working with Aboriginal people. This local person constantly balances competing cultural priorities with research protocols\(^1\). They are required to interpret complex concepts between two different world views, often in multiple languages. This representative needs to be respected by the community and well versed in the Western and Aboriginal way of knowing\(^1\). A local Aboriginal researcher who is a nominated representative of the community should collaborate in the design of a project that is working with their community from the beginning to the end. Co-authors of this paper and the Community Navigators for the Picture Talk...
Project are examples of local Aboriginal researchers who have collaborated on a research project. The second policy recommendation we make is:

2. Research protocols and ethical guidelines for research with remote Aboriginal communities should require external researchers to collaborate with a nominated representative of the Aboriginal community who holds local respect and has strong cultural knowledge. This Aboriginal research partner should inform the research project from the protocol design to completion of the project and delivery of results.

Researchers should have flexible timelines when conducting research in the Fitzroy Valley. Access to some remote Aboriginal communities may only occur at certain times of year due to flooding of the roads from the Wet Season and this must be taken into account when designing a research timeline. Time also needs to be invested by external researchers to establish trusting relationships with the community prior to the commencement of a project. When seeking consent from a community and individuals, it may require more than one meeting before participants understand what research is about. Time might be needed for individuals to meet with certain family members or other supports for advice or approval to be able to participate. In addition to this, time needs to be allowed for unexpected circumstances which might arise such as the death of a community member. In the Kimberley, people are connected through kinship and language groups and there are very large family groups who may go into mourning known as Sorry Business in the event of a death in the community. It has a ripple effect on the whole community. Researchers need to be respectful of such events and allow time for those involved to mourn. This might affect a research timeline. The onus should be put on the research funding body who is driving this pressure of time. Our third policy recommendation is:

3. Research protocols and ethical guidelines for research with remote Aboriginal communities should require funding bodies to be more flexible in their timelines allowing for unexpected cultural obligations.

Conclusion

Through interviewing Aboriginal community leaders of the Kimberley, the Picture Talk Project highlights the need for a change in research policy. The three recommendations we make are as follows:

1. Research protocols and ethical guidelines for research with remote Aboriginal communities should require research funding bodies to be responsive to the research needs identified by the community.

2. Research protocols and ethical guidelines for research with remote Aboriginal communities should require external researchers to collaborate with a nominated representative of the Aboriginal community who holds local respect and has strong cultural knowledge. This Aboriginal research partner should inform the research project from the protocol design to completion of the project and delivery of results.

3. Research protocols and ethical guidelines for research with remote Aboriginal communities should require funding bodies to be more flexible in their timelines allowing for unexpected cultural obligations.
All researchers need to acknowledge the world-view of their participants. It is important for research policies and timelines to be culturally sensitive, collaborative and flexible when working with Aboriginal communities. Through positive research partnerships, new understandings will arise. The impacts of which will be long lasting.

References


17. NHMRC. Values and Ethics: Guidelines for Conduct of Aboriginal and Torres Strait Islander Health Research. Australia 2003.


**Presenter**

Dr Emily Fitzpatrick BMedSci(Hons), MBBS, DCH started this research journey while working as a Junior Medical Officer for the Children’s Hospital at Westmead. She was taking a lunch break while attending a Grand Rounds lecture where she heard about The Lililwan Project. This fetal alcohol spectrum disorder (FASD) prevalence study was conducted in collaboration with Aboriginal communities and visiting researchers. FASD was thought to be affecting the next generation of Aboriginal children, who were having trouble remembering their dreamtime stories. Dr Fitzpatrick volunteered a year of her time as a doctor and a researcher in supporting this community-based project. Following this, Aboriginal leaders invited Dr Fitzpatrick to lead The Picture Talk Project to review the positive community engagement and consent process and explore what makes research culturally respectful. This is part of her doctorate with the University of Sydney was supervised by Prof Elliott, Assoc/Prof Martiniuk, Ms D’Antoine and Dr Macdonald. She also receives cultural supervision from Ms June Oscar, Ms Maureen Carter and Mr Tom Lawford, Aboriginal leaders of the Kimberley. In addition, Dr Fitzpatrick is training to be a General Paediatrician with an interest in Aboriginal health and continues to work for the Children’s Hospital at Westmead in Sydney.